National Library of Canada
Bibliothèque nationale du Canada

Canadian Theses Service
Service des thèses canadiennes

Ottawa, Canada
K1A 0N4

NOTICE

The quality of this microform is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Reproduction in full or in part of this microform is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30, and subsequent amendments.

AVIS

La qualité de cette microforme dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

La reproduction, même partielle, de cette microforme est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30, et ses amendements subséquents.

NL-339 (r. 88/04) c

Canada

UNIVERSITY OF ALBERTA

LIVING SITUATION ARRANGEMENTS: ROLE IN PREDICTION OF SELF-ESTEEM OF PEOPLE WHO ARE QUADRIPLEGIC

BY

ABIGAIL JANE PARRISH-CRAIG

(C)

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE

OF MASTER OF EDUCATION

IN

COUNSELLING PSYCHOLOGY

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

FALL 1990

National Library of Canada
Bibliothèque nationale du Canada

Canadian Theses Service
Service des thèses canadiennes

Ottawa, Canada
K1A 0N4

The author has granted an irrevocable non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of his/her thesis by any means and in any form or format, making this thesis available to interested persons.

L'auteur a accordé une licence irrévocable et non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de sa thèse de quelque manière et sous quelque forme que ce soit pour mettre des exemplaires de cette thèse à la disposition des personnes intéressées.

The author retains ownership of the copyright in his/her thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without his/her permission.

L'auteur conserve la propriété du droit d'auteur qui protège sa thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

ISBN 0-315-64886-4

CONSULTING PSYCHOLOGISTS PRESS, INC.

577 College Avenue (P.O. Box 60070), Palo Alto, CA 94306 (415) 857–1444

Abigail Parrish-Craig
501, 10950-82 Ave.
Edmonton, Alberta
T6G 2R9
Canada

Customer # _____
Purchase order # _____
Product # _____
Quantity _____
Price _____

In response to your request of 1/12/90 (Date) permission is hereby granted to you to

for ☒ research ONLY ☐ commercial use ☐ clinical use

subject to the following restrictions:

(a) Any material used must contain the following credit lines:

"Reproduced by special permission of the Publisher, Consulting Psychologists Press, Inc., Palo Alto, CA 94306,

from Coopersmith Self-Esteem Inventory

by Stanley Coopersmith © _____

Further reproduction is prohibited without the Publisher's consent."

(b) None of the materials may be sold or used for purposes other than those mentioned above.

(c) One copy of any material reproduced will be sent to the Publisher to indicate that the appropriate credit line has been used.

(d) Payment of a reproduction fee of _____

(e) Abigail Parrish-Craig agree(s) to assign all right, title, and interest in translations, versions, and/or modifications of this instrument to CPP or as directed by CPP.

CONSULTING PSYCHOLOGISTS PRESS, INC.

By Eric Kaufman Date 1/23/90

Permissions Department

author

ABIGAIL PARRISH-CRAIG

501, 10950-82 Avenue
Edmonton, Alberta
T6G 2R9

July 11, 1990

American Psychological Association
1200 Seventeenth Street N.W.
Washington, DC 20036

To whom it may concern:

I am writing to request written permission to reprint part or all of the Rotter Internal-External scale in an appendix of my thesis completed for the degree of Master of Education in Counselling Psychology at the University of Alberta.

My thesis is entitled "Living situation arrangements: Role in prediction of self-esteem of people who are quadriplegic". Locus of control is included as a predictor variable. I obtained the survey from the following reference:

Rotter, J.B. (1966). Generalized expectancies for internal versus external control of reinforcement. Psychological Monographs, 80, Whole No. 609 (1-28).

Please forward your response to myself at the above address.

Thank you for your assistance.

Sincerely,

Abigail Parrish-Craig

Abigail Parrish-Craig

APA permission granted without fee provided author permission is obtained and reprint includes a full bibliographic citation and the following notice: Copyright 1966 by the American Psychological Association. Reprinted (or Adapted) by permission.

Karen A. Thomas 7-18-90

Permissions Office
American Psychological Association

THE UNIVERSITY OF CONNECTICUT

The College of Liberal Arts and Sciences
Department of Psychology
Box U-20, Room 107
406 Cross Campus Road
Storrs, Connecticut 06268

August 18, 1990

Abigail Parrish-Craig
501, 10950-82 Avenue
Edmonton, Alberta
T6G 2R9, Canada

Dear Ms. Parrish-Craig:

You have my permissionto include the I-E Scale in the Appendix of your thesis.

Very truly yours,

Julian B. Rotter

Julian B. Rotter
Professor of Psychology

JBR/isw

An Equal Opportunity Employer

UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR: ABIGAIL JANE PARRISH-CRAIG

TITLE OF THESIS: LIVING SITUATION ARRANGEMENTS: ROLE IN PREDICTION OF SELF-ESTEEM OF PEOPLE WHO ARE QUADRIPLEGIC

DEGREE: MASTER OF EDUCATION

YEAR THIS DEGREE GRANTED: 1990

PERMISSION IS HEREBY GRANTED TO THE UNIVERSITY OF ALBERTA LIBRARY TO REPRODUCE SINGLE COPIES OF THIS THESIS AND TO LEND OR SELL SUCH COPIES FOR PRIVATE, SCHOLARLY OR SCIENTIFIC RESEARCH PURPOSES ONLY.

THE AUTHOR RESERVES OTHER PUBLICATION RIGHTS, AND NEITHER THE THESIS NOR EXTENSIVE ABSTRACTS FROM IT MAY BE PRINTED OR OTHERWISE REPRODUCED WITHOUT THE AUTHOR'S WRITTEN PERMISSION.

Abigail Parrish-Craig

501, 10950-82 Avenue

Edmonton, Alberta

T6G 2R9

Date: August 29, 1990

UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

THE UNDERSIGNED CERTIFY THEY HAVE READ, AND RECOMMEND TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH FOR ACCEPTANCE, A THESIS ENTITLED **LIVING SITUATION ARRANGEMENTS: ROLE IN PREDICTION OF SELF-ESTEEM OF PEOPLE WHO ARE QUADRIPLEGIC** SUBMITTED BY **ABIGAIL JANE PARRISH-CRAIG** IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF EDUCATION IN COUNSELLING PSYCHOLOGY.

Richard Sobsey

DR. RICHARD SOBSEY - SUPERVISOR

Ronna Jevne

DR. RONNA JEVNE

J.W. Vargo

DR. JAMES VARGO

DATE: July 18, 1990

DEDICATION

To my husband, Tom, for his courage and example in coping with the challenges of quadriplegia.

ABSTRACT

This thesis presents the results of a correlational study designed to evaluate the role of certain environmental and psychosocial factors in the prediction of self-esteem of people who are quadriplegic due to spinal cord injury. The research is based on a multivariate systems approach to understanding adjustment to spinal cord injury. The study primarily focuses closely on the influence of certain aspects of the living situation, namely housing and attendant care. These variables are identified by the Independent Living paradigm as fundamental to the successful accomplishment of independent living after disability. This paradigm proposes that the problems facing disabled people primarily originate in the environment and that successful independent living is more probable if environmental barriers are replaced with community-based services, programs, and resources that permit disabled people to experience control and choice in their lives. Consequently, the salience of variables measuring perceived control over attendant care and perceived independence in current living situation is also included in this study.

The random sample numbering 75 was selected from the population of quadriplegic individuals living in the central region of Alberta. The descriptive results suggest that, generally, self-esteem among respondents is strong. The locus of control results indicate an average trend towards an internal expectancy of control. Furthermore, descriptive results of living situation characteristics

demonstrate that people are living in a wide variety of circumstances but primarily individuals are dependent on a single primary care provider. The correlational analysis yielded several statistically significant correlations among variables. Living in a fully adapted environment correlated with locus of control, perceived control over attendant care, and perceived independence. Living in community-based (as opposed to institutional) settings also correlated with perceived control over attendant care. Other environmental variables failed to correlate with self-esteem, locus of control, perceived control, or perceived independence. Using multiple regression analysis, two predictor variables, perceived control and locus of control, accounted for approximately 24% of the variance in self-esteem scores. The significance of control in the sense of well-being experienced by quadriplegic individuals is discussed. Conclusions, limitations, and implications of the study's results are reviewed.

ACKNOWLEDGEMENT

The author acknowledges her debt and gratitude to the following for their contribution to the completion of this thesis:

Dr. Richard Sobsey, for his valuable guidance and feedback in all aspects of this research;

Dr. Ronna Jevne and Dr. James Vargo, for their honest and critical review of the work;

The Canadian Paraplegic Association, in particular, Larry Pempeit, Jodi Abbott, Guy Coulombe, Donna Boychuk, and Clancy White, for the generous donation of time and effort in the data collection procedure;

Meg Parrish, my mother, for her careful review of literary aspects of the text;

All my family members and friends, for listening to my anxieties and concerns and for the unconditional support that helped me to complete the process.

Heartfelt gratitude is expecially extended to the people who participated as members of the sample included in this study. Without their generous cooperation and willingness to contribute their time and themselves, this research study would not have been possible or valuable.

TABLE OF CONTENTS

CHAPTER I INTRODUCTION 1

STATEMENT OF THE PROBLEM 3

HYPOTHESES 3

LIMITATIONS OF THE STUDY 4

DEFINITION OF TERMS 5
QUADRIPLEGIA 5
SELF-ESTEEM 6
LOCUS OF CONTROL 6

CHAPTER II LITERATURE REVIEW 7

BACKGROUND INFORMATION 7
SPINAL CORD INJURY 7
DEMOGRAPHIC INFORMATION 10

SYSTEMS APPROACH TO ADJUSTMENT 11

INDEPENDENT LIVING MODEL 18

CONTROL AND INDEPENDENCE 20

LIVING SITUATION ARRANGEMENTS 24

CHAPTER III METHODS AND PROCEDURES 27

SAMPLE SELECTION 27

DESCRIPTION OF THE SAMPLE 29

(CHAPTER III CONTINUED)

INSTRUMENTS 32
INDIVIDUAL DATA SHEET 32
COOPERSMITH SELF-ESTEEM INVENTORY - ADULT FORM 35
ROTTER'S INTERNAL-EXTERNAL SCALE 36
ATTENDANT CARE QUESTIONNAIRE 37

DATA COLLECTION PROCEDURE 38

CHAPTER IV RESULTS 41

DESCRIPTIVE STATISTICS 41

CORRELATIONAL ANALYSIS 43
SELF-ESTEEM 44
LOCUS OF CONTROL 45
PERCEIVED CONTROL 47
PERCEIVED INDEPENDENCE 48
OTHER SIGNFICANT CORRELATIONS 49

REGRESSION ANALYSIS 50

COMPARISON OF GROUPS 51

CHAPTER V DISCUSSION 54

SELF-ESTEEM 54

IMPORTANCE OF CONTROL 56

INDEPENDENCE 58

LIVING SITUATION ARRANGEMENTS 61

ROLE OF DEMOGRAPHIC VARIABLES 63
AGE 63
LEVEL OF INJURY 65
EDUCATIONAL LEVEL 65

TRIESCHMANN'S MODEL REVISITED 66

(CHAPTER V CONTINUED)

EXPLANATIONS FOR UNSUPPORTED HYPOTHESES 68

CHAPTER VI SUMMARY, CONCLUSIONS, LIMITATIONS, AND IMPLICATIONS 70

SUMMARY 70
THE PROBLEM 70
METHOD 71
RESULTS 72

CONCLUSIONS 74

LIMITATIONS 76

IMPLICATIONS 77

REFERENCES 82

APPENDIX 1 INDIVIDUAL DATA SHEET 89

APPENDIX 2 COOPERSMITH SELF-ESTEEM INVENTORY (EXCERPT) 92

APPENDIX 3 ROTTER SCALE 94

APPENDIX 4 ATTENDANT CARE QUESTIONNAIRE 99

APPENDIX 5 CONSENT FORM 101

LIST OF TABLES

TABLE 1. Sample Characteristics: Age at Injury and Current 29

TABLE 2. Sample Characteristics: Level of Injury 30

TABLE 3. Sample Characteristics: Employment Status Pre-Injury and Current 31

TABLE 4. Means, Standard Deviations, and Ranges of Continuous Variables 41

TABLE 5. Frequencies and Percentage of Subjects According to Characteristics of the Living Situation 42

TABLE 6. Major Correlates of Self-Esteem and Locus of Control 44

TABLE 7. Major Correlates of Perceived Control and Perceived Independence 47

TABLE 8. Stepwise Regression Analysis on Self-Esteem 50

TABLE 9. Frequencies and Percentage of Subjects According to Living Arrangement 52

CHAPTER I

Introduction

The most commonly known consequence of spinal cord injury (SCI) is physical paralysis. However, the effects usually extend far beyond this obvious one. The injured individual faces the challenge of adjustment, not only to the physical change, but also to the psychological, social, vocational, financial, sexual, and many other changes incurred as a result of the injury (Trieschmann, 1988).

The challenge of adjustment to SCI has been described by people experiencing it personally (Caywood, 1984; Ragone, 1987) and by rehabilitation psychologists (Crewe & Krause, 1987; Trieschmann, 1988; Woodbury & Redd, 1987). People with SCI need to acquire medical knowledge and familiarity with their injury, its physical aspects, and their individual experience of these physiological changes. They learn new methods of attending to basic skills of toileting, self-care, and personal hygiene. They have to learn to use a wheelchair for basic mobility and other equipment to accomplish necessary daily tasks. They need to redesign their home or move to new accommodation in order to benefit from a wheelchair accessible living environment. If they choose to become employed, they probably need to choose a new vocation and to undergo training. When seeking employment, they often cope with and challenge the architectural and attitudinal barriers facing people with disabilities. In order to manage the

expenses imposed by the disability, they usually need to seek financial support from public and charitable sources or spend greater than average personal resources.

Given the enormity and scope of this challenge, considerable attention has been focused on the study of adjustment to SCI and on the identification of factors that correlate with, and may be predictive of, successful adjustment to the disability. Trieschmann (1980, 1988) has been rigorous and extensive in her reviews of the literature investigating adjustment to SCI. She observes that a physical disability alters the balance of life and requires that an adjustment be made. Furthermore, adjustment is a fluctuating state in people's lives (disabled and non-disabled alike) and, at any time, it is achieved by obtaining a balance among three major categories of factors: biological-organic state, psychosocial characteristics and resources, and environment. She lists multiple variables under each category that interact and influence the adjustment outcome. The dynamic balance among these variables determines the adjustment of an individual at any time. Although SCI most obviously influences the organic-biological dimension of the individual, Trieschmann's conceptual framework assumes that adjustment involves attaining a new balance in the mind-body system within the environment in which the person lives. The process is complex and idiosyncratic.

Most people who become disabled as the result of SCI appear to adjust reasonably well (Green, Pratt, & Grigsby, 1984; Krause & Crewe, 1987). The scientific interest is in understanding how this is so. This study investigated

aspects of this person-environment relationship among people who have incurred SCI and, more specifically, people who are quadriplegic as a result. (Quadriplegia will be defined more completely in a future section). Living situation arrangements were being analyzed with respect to their role in predicting the self-esteem of this sub-group of spinal cord injured people.

Statement of the Problem

The principal questions posed by this study are the following:

1. For people who are quadriplegic, are there significant relationships among the criterion variable of self-esteem and the predictor variables of locus of control, perceived control over attendant services, perceived independence in current living situation, and five objectively measured characteristics of the living situation (related to housing and attendant care)?

2. If so, how do these predictor variables contribute to the prediction of self-esteem?

Hypotheses

1. External locus of control will be negatively related to self-esteem, perceived control over attendant services, and perceived independence in the living situation. (High scores on Rotter's Internal-External scale indicate an external locus of control).

2. Living at home or in a community-based environment (as opposed to an

institutional environment) will be positively related to self-esteem, perceived control, and perceived independence.

3. For people who live at home or in a community-based environment, access to a staff of care providers (as opposed to a single primary care provider) will be positively related to self-esteem, perceived control, and perceived independence.

4. The absence of a money issue related to the expense of attendant care will be positively related to self-esteem, perceived control, and perceived independence.

5. Actual control over attendant care (hiring, training, and/or evaluation of staff) will be positively related to self-esteem, perceived control, and perceived independence.

6. For people who live at home or in a community-based environment, living in an environment that is fully adapted to the individual's physical disability will be positively related to self-esteem, perceived control, and perceived independence.

7. The predictor variables, either alone or in combination, will account for significant variance in self-esteem. The coefficient of determination (R^2) will be greater than zero.

Limitations of this study

Although the broader topic addressed by this research pertains to

adjustment to SCI, this study limited its scope of investigation in a few significant ways.

First, the study's sample included only people who are quadriplegic whereas SCI may have many other resulting effects. As a result, spinal cord injured people who are paraplegic or ambulatory in spite of cervical damage were not included in the sample. A primary focus of this study was to investigate attendant care arrangements which are, generally, irrelevant issues to spinal cord injured people other than those with quadriplegia. Therefore, the results are generalizable to people who are quadriplegic and not necessarily to all people with SCI.

Second, the criterion variable used in this study was self-esteem. Self-esteem is not necessarily an adequate measure of adjustment particularly as it has already been described as a broader, more fluctuating ongoing attempt to attain a balance in the biological, psychosocial, and environmental factors of a person's life. However, since self-esteem is generally viewed and has been supported as a personal judgment of worthiness (Coopersmith, 1967), it is a relevant aspect of adjustment. It is also readily measured.

Definition of terms

Quadriplegia.

Quadriplegia refers to paralysis of all four extremities (Buchanan, 1987). It results when an injury occurs to the spinal cord in the cervical region (between C1

and T1). Paraplegia refers to paralysis of the two lower extremities and results when an injury occurs to the spinal cord in the thoracic, lumbar, or sacral region.

Self-esteem.

Self-esteem is defined as the evaluation a person makes about him- or herself (Coopersmith, 1967, 1984). Overall, self-esteem is an expression of the extent to which a person believes him- or herself to be competent, successful, significant, and worthy. It is a personal judgment or evaluation of worthiness expressed in the attitudes a person holds toward the self.

Locus of control.

The concept of locus of control derives from social learning theory and refers to the degree to which individuals believe that rewards and reinforcements result from their behavior (Rotter, 1966). People are described as having an internal locus of control if they believe that the rewards and reinforcements they experience are to a large extent the result of their own skills, abilities, and choices. They believe they have considerable control over their life. In contrast, people who have an external locus of control believe that rewards and reinforcement are not under their control but are more the result of fate, luck, chance, or powerful other people. They believe they have limited control over the events and outcomes in their life.

CHAPTER II

Literature Review

Spinal cord injury invariably upsets the balance of life and an adjustment must occur in order to establish a new balance. This literature review will summarize current knowledge and research in the following areas: background information including the physical effects of SCI and basic demographic information, a systems model of adjustment (Trieschmann, 1980, 1988) reviewing the evidence regarding the roles of biological-organic, psychosocial, and environmental variables, the Independent Living paradigm, the particular relevance of control and independence, and the current living situations of spinal cord injured people.

Background Information

Spinal cord injury.

Spinal cord injury causes varying degrees of motor, sensory, and other physical impairments that are dependent on the extent of injury and the level of injury (Buchanan, 1987; Zejdlik, 1983). The extent of injury describes whether the lesion is complete or incomplete. By definition, a complete injury has occurred when there is no intact sensory or motor function below the neurological level of injury (Buchanan, 1987). In the case of an incomplete injury, there are some

motor and/or sensory functions still fully intact. The potential range of function after incomplete injuries is vast. Some people have small amounts of movement or sensation whereas others have nearly no deficits in movement or sensation.

Level of injury affects residual function. Generally, the higher the level of injury in the vertebral column, the more extensive the physical disability. However, it is important to note that the vertebral level of injury does not necessarily equate with the neurological level of injury (Fischer, 1989). The first refers to the actual bones in the vertebral column that incurred injury. The second refers to the level of function that remains intact regardless of vertebral damage. Neurological level of injury is established as the lowest level in which functional motor power and sensation remain intact after SCI.

General information about the functional abilities associated with levels of injury has been described in the literature and will be summarized (Alvarez, 1985; Buchanan, 1987; Phillips, Ozer, Axelson, & Chizeck, 1987). There are seven cervical vertebrae and eight spinal nerves in the neck region (C1-C8). Injuries at the first and second cervical levels (C1 and C2) lead to impaired function below the chin and, if complete injuries, are accompanied by an inability to breathe without the use of a respirator. These people are completely dependent for all care and limited to the use of sip and puff mechanisms to operate wheelchair, computer, and environmental control units.

Injuries at C3 cause paralysis below the neck. There may be some need for a respirator and may be some shoulder movement. Total assistance in daily

activities is required. C4 injuries often free the person from reliance on a respirator but there is usually no functional use of the arms. Total assistance is required although independent mobility with a head or chin operated wheelchair is probable.

People with C5 injuries are able to use their shoulders and biceps and, therefore, have some arm mobility. They can usually feed themselves and, with adaptations, can often perform minor activities of daily living. Assistance with most other aspects of daily living is commonly necessary.

At the C6 level, functional use of wrist extension is usually present. As a result, more independence in activities of daily living becomes feasible. The person is more likely to be able to transfer him- or herself to and from a wheelchair and to be able to use hand function for more tasks. At C7, the triceps are intact. With nearly full arm function, independence becomes very feasible. Absence of finger function and trunk balance may impede this achievement. Functional independence may be challenging because the energy and time required to complete daily activities can be exhausting.

In complete SCI, sensory impairment generally coincides with areas of motor loss (Buchanan, 1987; Phillips, Ozer, Axelson, & Chizeck, 1987; Zejdlik, 1983). Below the level of lesion, there is loss of sensation of temperature, touch, pain, and proprioception. These sensory losses have important implications for health maintenance. In order to maintain intact, healthy skin, the person needs to attend to regular pressure relieving and to the prevention of burns and other

injuries that may require long treatment time to heal.

Concomitant with complete SCI are loss of voluntary bladder and bowel control (Zejdlik, 1983). As a result, people with spinal injury have to learn, and live with, different techniques for managing bladder and bowel function. Bladder management is usually achieved with a catheterization program. Bowel routines are established to train the bowel to empty regularly. The procedures require time to perform. People who are quadriplegic usually require assistance in accomplishing these routines.

Spinal cord injury has many other physical implications. These include altered sexual function, spasticity, autonomic dysreflexia, respiratory impairment, and pain (Phillips, Ozer, Axelson, & Chizeck, 1987; Zejdlik, 1983). These physical complications are often experienced by people with quadriplegia.

Demographic information.

Stover & Fine (1986, 1987) have reviewed extensive demographic information on SCI collected in the United States. Spinal cord injury is mainly a male condition (males 82%, females 18%). It primarily occurs to young people: 61.1% of those incurring SCI are in the 16-30 year old age group. The mean age of onset is 29.7 years, median age is 25 years, and the modal age is 19 years. At the time of injury, 58.8% are single, 29.3% married, 59.9% employed, 19.7% students, 12.5% unemployed, 3.4% retired, 2.5% homemaker, and 2% unknown. Regarding educational level completed at time of injury, 15% have grade eight or less, 28% have some high school, 34% are high school graduates, and 24% have

at least some college or university education (Young, Burns, Bowen, & McCutcheon, 1982).

Systems Approach to Adjustment

Trieschmann (1980, 1988) has proposed a conceptual framework that attempts to explain the adjustment of spinal cord injured people. She hypothesized that adjustment (really for all people) is the function of three sets of variables: biological-organic, psychosocial, and environmental. At any time, people experience fluctuations in the balance between these variables and a new homeostasis is sought by altering other factors subsumed under these three categories.

The biological variables include those that derive from a genetic and organic basis. Included among these, Trieschmann lists general health, bladder and bowel function, pain, endurance, strength, respiratory status, perceptual motor coordination, intelligence and cognitive ability, and aptitudes. Extensive investigations have been conducted to examine the role of age, and severity of disability (other biological factors), in adjustment to SCI.

As previously reported, the majority of people sustaining spinal cord damage are under age 30 at the time of injury. The population is predominantly young. Generally observed is a negative correlation between age and various indices of adjustment such as self-concept (Green, Pratt, & Grigsby, 1984),

productivity (Kemp & Vash, 1971), and mental adjustment (Kerr & Thompson, 1972). A positive correlation was reported between age and depression (Judd, Burrows, & Brown, 1986). Individuals injured at younger ages generally seem to adjust to their changed circumstances more effectively than older people.

Several studies have investigated differences in adjustment that are related to level of injury. Quadriplegia obviously causes more severe disability than paraplegia. Given the greater physical challenges, quadriplegia is expected to be more difficult to adjust to than paraplegia. It also seems intuitive that, among people who are quadriplegic, higher levels of spinal injury would pose more adjustment challenges than lower level injuries. Contrary to expectations, the data do not support differences in adjustment that correlate with severity of disability. No differences were observed in emotional reaction to disability (Cook, 1979), acceptance of disability (Woodrich & Patterson, 1983), or in Minnesota Multiphasic Personality Inventory (MMPI) profiles (Thompson & Dexter, 1980). Anderson and Andberg (1979) found that a group of paraplegics had a higher incidence of pressure sores than a group of quadriplegics. They also reported that satisfaction with activities of life was predictive of days lost due to pressure sores. They concluded, therefore, that certain psychological variables, and not necessarily severity of disability, influenced incidence of pressure sores. Evidence suggesting that severity of disability directly affects successful adjustment is absent.

However, there is some evidence that severity of disability interacts with other psychosocial and environmental variables to influence psychological well-

being. Kemp & Vash (1971) observed an interaction between degree of paralysis and interpersonal support. There was no significant difference in productivity between paraplegic and quadriplegic subjects who reported high interpersonal support, but quadriplegic subjects with low interpersonal support were less productive than their paraplegic counterparts. Thompson and Dexter (1980) evaluated the MMPI profiles of a large group (n = 176) of newly injured people. Comparison of the groups of paraplegic and quadriplegic respondents revealed that the latter group experienced more distress such as feelings of isolation and detachment from peers. These results illustrate the more complex involvement of biological, psychosocial, and environmental factors in influencing ultimate outcome.

Trieschmann (1988) defined the psychosocial variables as all the intrinsic characteristics that make up personality, and include other integral aspects of the person such as education, work history, cultural and ethnic group. In addition, she included inclinations such as will to live, tendency to take responsibility for self, style of coping with stress, self-confidence, judgment, problem-solving skill, belief system, and others under this category.

In terms of psychosocial adjustment to SCI, many authors have expounded on the necessary stages of psychological adjustment (Bracken, Shepard, & Webb, 1981; Hohmann, 1975; Kerr & Thompson, 1972; Livneh, 1986; Stewart, 1977-78). Although these explanations vary somewhat in description of the stages, common themes include an expectation of denial, anger, depression, and eventual

acceptance of the injury. Although the model is still used in clinical settings, empirical data neither accompany the description of the process nor are documented in other research to demonstrate that it is a valid explanation of the experience. Until scientific support for the stages of adjustment is available, generalizations regarding a common process of adjustment experienced by all spinal cord injured people need to be cautious.

Several researchers have attempted to isolate personality characteristics that are related to successful adjustment to SCI. Extraversion has been identified as a characteristic associated with both likelihood of sustaining injury and with successful adjustment (Malec, 1985). Locus of control has been empirically supported as a personality characteristic correlated with adjustment. Investigations of this construct among spinal injured samples have demonstrated an internal locus of control to correlate with several indices of adjustment such as acceptance of disability (Mazzulla, 1984), less emotional distress (Shadish, Hickman, & Arrick, 1981), successful rehabilitation (Swenson, 1976), and less time spent hospitalized with preventable medical conditions (Anderson & Andberg, 1979).

Kemp and Vash (1971) conducted a large study measuring multiple variables and correlated them with ratings of productivity (defined as degree of involvement in a variety of activities). Certain factors were highly correlated. Regression analysis indicated that reported number of goals contributed most to the prediction of productivity. Furthermore, the more productive people in the

study reported goals of a vocational and family-interpersonal nature, whereas less productive people tended to have avocational and physical (recovery) goals. Scales of the California Psychological Inventory that were significantly correlated with productivity included dominance, social presence, and self-acceptance. Subjects rated as low in productivity registered scores below the mean on many scales. In this same study, tests of creativity were administered and yielded results indicating that highest scores were obtained by productive subjects. Although these were not tests of intellectual ability, they did assess creative problem solving ability.

Completed education level has been hypothesized to correlate with adjustment outcome. Years of completed education have been significantly correlated with various dimensions of self-concept (Green, Pratt, & Grigsby, 1984) and with hospital ratings of adjustment (Nickerson, 1971). Other studies have failed to show similar significant relationships (Kemp & Vash, 1971; Mazzulla, 1984). The results are inconsistent regarding the influence of educational achievement in predicting adjustment to disability.

Although there appear to be some personality and psychosocial characteristics that correlate with successful adjustment, considerable unexplained variance remains. This result may stem from the erroneous assumption that there is a particular psychological reaction to spinal injury or that there are personality characteristics that exist in isolation from environmental factors that explain successful versus poor outcomes.

Trieschmann's model also proposed that environmental variables are relevant to predictions of successful adjustment. Adjustment to disability does not occur in isolation from a person's living circumstances. The "handicapping" role of the environment has been frequently discussed in the literature (DeLoach & Greer, 1981; Vash, 1981). That is, people with disabilities become handicapped when the environment hampers their accomplishment of a task that they could perform if the environment was appropriate to the physical disability.

Some evidence of the role of environment in adjustment to SCI derives from cross-cultural research. Jenik (1982) reported that in his Swiss sample of spinal cord injured persons, 77.8 % were working or planning to do so, 67.8% were driving, and 25% had improved their education since injury. In contrast, Nwuga (1979) found that most of his Nigerian sample of spinal injured had died within one year of hospital discharge and only one was employed. A Japanese study (Nakajima & Honda, 1988) reported that 50% of their large sample (n=926) complained of poor physical health, that 44% of the quadriplegic patients were confined to their homes, that the employment rate was 30% of which 46% were self-employed. None of these studies provided contextual information regarding community and government resources or programs. It seems plausible that the significant cross-cultural differences may be attributed to differences in standard of living, medical care, environmental accessibility, community and government support programs between these countries.

North American studies have demonstrated the influence of certain environmental factors. For example, interpersonal support has been repeatedly correlated positively with adjustment (Decker & Schulz, 1985; Kemp & Vash, 1971; Rogers & Figone, 1979; Tucker, 1980). Spinal injured people reporting high levels of emotional, cognitive, and physical support tend to experience greater life satisfaction, higher productivity, and more positive self-esteem.

Financial resources and socio-economic status have been correlated with measures of adjustment in samples of spinal cord injured people (Decker & Schulz, 1985; Nickerson, 1971) although not consistently (Green, Pratt, & Grigsby, 1984). A recent study has demonstrated that a group of spinal cord injured people who had adequate resources, matched with a group of non-disabled people, showed similar levels of activity and reported fulfilling satisfactory lives (Brown, Gordon, & Ragnarsson, 1987). These results suggest that, if people have adequate financial resources, there is little difference in quality and nature of life if a person has a disability. However, there are many people with severe disabilities, whose incomes fall below the poverty line, who are deemed to be successful independent living role models (Denson, 1987). Although the evidence suggests that disabled people who have adequate financial resources appear to be productive and well-adjusted, there are many without such resources who also do well.

These data demonstrate again the vital interaction between psychosocial and environmental variables in explaining adjustment outcome after SCI. Socio-

economic status is generally related to educational level and occupational status. It follows that people with more education will have a higher occupational status and, therefore, a higher socioeconomic status. As a result, these people are more likely to have the personal resources to cope with challenging life circumstances and to have adequate funds to cover the extraordinary costs of disability such as medical supplies, medication, equipment, transportation, housing modifications, and attendant care. However, after spinal injury, most people face changed occupational status, reduced financial status, and increased costs. Most disabled people live below the poverty line (Statistics Canada, 1989). Regardless, many cope adequately with disability. An aspect of this study was to evaluate if people who are quadriplegic, and who have reliable access to funds to pay for attendant care, experience higher self-esteem and perceptions of control and independence.

This discussion on the role of environmental variables in adjustment to SCI provides the basis for this research. Understanding the amount of variance in adjustment scores accounted for by environmental factors has bearing on many practical and political decisions regarding disabled people, and is also needed to support the goals and principles of the Independent Living movement.

Independent Living Model

The philosophy of the Independent Living movement offers a particular conceptualization of the experience and desired outcomes for disabled people. Independent living has been defined as follows:

> Control over one's life, based on the choice of acceptable options that minimize reliance on others managing one's affairs, participating in day-to-day life in the community, fulfilling a range of social roles, making decisions that lead to self-determination, and the minimization of physical or psychological dependency upon others. (Frieden, Richards, Cole, & Bailey, 1979).

The central underlying concepts are control, self-determination, choice, and freedom. Independence is achieved when disabled individuals choose their living situation within society in such a way that they achieve power over their social environment (DeJong, 1979).

The Independent Living paradigm has been contrasted with the rehabilitation paradigm associated with the medical model (DeJong, 1979). The principal differences between these two models are the identification of the locus of the problem for disabled people and, consequently, the proposed solution. The Independent Living model views the problem as being generated from the environment whereas the medical model identifies the individual patient as the locus of the problem. Subsequently, the intervention points for solving the problem vary between the two viewpoints. The Independent Living paradigm's objectives are to alter the environment, in order to remove the barriers that limit choices, and to develop consumer controlled services. In contrast, the medical model's solutions usually entail attempts to change the individual in areas such as self-care, employability, and activities of daily living so that he or she can manage in society as it is.

The Independent Living movement assumes that quality of life and successful independent living outcomes are contingent upon environmental accessibility (DeJong, Branch, & Corcoran, 1984). Specific environmental factors that are essential to achieving these ends include appropriate housing, attendant care services, accessible transportation, and community accessibility (Crewe & Zola, 1983; Frieden & Cole, 1985). This study investigated the extent to which specific aspects of the attendant care and housing situation, as well as individual characteristics, influence the self-esteem of people who are quadriplegic.

Control and Independence

Two key elements are emphasized and are relevant to this discussion: control and independence. The two concepts are inextricably linked since they include each other in their respective definitions. Webster's Third Dictionary (1981) defined control as "power or authority to guide or manage" (p.496) and independence as "not subject to control or not requiring or relying on someone else" (p.1148). The relevance of these concepts to this research will be explored here.

Many psychological researchers have investigated control and its relationship to stress and coping skills (Averill, 1973; Pervin, 1963). Lack of control has been found to be more anxiety provoking for people who generally have an internal expectation of control (Bowers, 1968) and subjects' responses to situations offering different levels of decisional control were influenced by their

expectation of control (Lewis & Blanchard, 1971).

Locus of control has been associated with effective social readjustment (Crandall & Lehman, 1977; Phares, 1968). In the literature on adjustment to SCI, similar results have been obtained. Spinal cord injured people with an external locus have been found to experience more distress than those with an internal locus regardless of length of time since injury (Shadish, Hickman, & Arrick, 1981). Dinardo (cited in Trieschmann, 1988) found spinal cord injured people with an internal expectancy to be less depressed and to have better self-concepts than those with an external locus. Crisp (1984) reported that spinal cord injured people with an internal locus of control were more productive after discharge from rehabilitation.

Level of injury has not differentiated people on the basis of locus of control (Crisp, 1984; Ferington, 1986). In other words, the amount of physical control over one's needs and circumstances has not been correlated with locus of control or other adjustment measures. It would appear that degree of psychological control is more important than actual physical control in relationship to measures of adjustment to disability.

Perceived control and preference for control have also been evaluated as salient variables. Depression has been negatively related to perceived control in a sample of hospitalized spinal cord injured individuals (Ferington, 1986). That is, subjects who had higher levels of perceived control tended to experience less depression. Furthermore, subjects who preferred control were found to have

decreasing depression as their level of perceived control increased.

Control is a fundamental concept within the Independent Living paradigm. For disabled people, self-determination and consumer control over the individual services which they receive are paramount to living independently (Coalition of Provincial Organizations for the Handicapped, 1986; Lord & Osborne-Way, 1987). Disabled individuals are expected to achieve more successful independent living and productivity when they realize a desired level of control in their living situation. Living situations vary in the actual control available to the disabled individual. Generally, people living in institutional environments have little or no control over staffing, although they may be able to achieve some control over their individual care. Other people have full control over the hiring, training, and supervision of attendants who provide required care. No studies have reported differences in the amount of perceived control experienced by spinal injured people living under various circumstances. Therefore, this was investigated in this study.

The concept of independence occupies a place in several realms of study: psychology, rehabilitation, and independent living. Personality theories have incorporated the concept of independence in various forms. Autonomy and freedom are commonly used synonyms. Erikson (1963), in his stage theory of childhood psychosocial development, theorized that the task of the second stage of development was autonomy, and that children at this stage need to start choosing to do things on their own within the guidelines of socially acceptable

behavior. Murray's personality theory (1938) included a list of needs of which autonomy is one. His definition was broad and comprehensive and included the following aspects: to get free, shake off restraint, break out of confinement; to resist coercion and restriction; to avoid or quit activities prescribed by domineering authorities; to be independent and free to act according to impulse; to be unattached, irresponsible; to defy convention. He assumed that people vary in the overall strength of this need in general and situationally. As with Trieschmann's systems approach to adjustment, Murray's personality theory incorporated the assumption that environmental characteristics and demands influenced personality and personal expression. Glasser's Control Theory (1984) has identified freedom as one of the four basic psychological needs. His conceptualization has primarily incorporated freedom of choice into the definition. He purports that people need to have options in their behavior in order to have this basic need fulfilled.

A major goal of physical rehabilitation is to maximize independence. Functional independence, the commonly understood meaning of this term, refers to the ability to complete on one's own activities of daily living such as self-care, mobility with a wheelchair, and advanced wheelchair skills (Granger & Greer, 1976; Keith, 1984). Independence is achieved when a person can attend to daily tasks with the least amount of assistance. Therefore, it is expected that people with more severe disabilities will achieve less independence. This does not necessarily mean that people who cannot look after their personal needs cannot

be independent.

In the study of people with disabilities, independence has been considered more broadly. Nosek, Parker, and Larsen (1987) investigated the relative influence of the psychological, social, and functional dimensions of independence in the independent living outcomes of adults with musculoskeletal impairments. Their results demonstrated that functional independence did not play a significant role in predicting independent living outcomes. However, psychological independence (as measured by Cattell's 16 Personality Factor scale) contributed significantly to the prediction. In other words, actual physical independence appears to be less critical to adjustment than psychosocial independence.

One emphasis of the Independent Living perspective is on choice. Independence is viewed as being able to choose one's lifestyle and living arrangements. Two people may be considered to be equally independent if one is living in a community environment and the other in an institution, if both have voluntarily selected their respective circumstances. The role of perceived choice and independence in current living situation were investigated in this study.

Living Situation Arrangements

People with severe disabilities live under a variety of different circumstances in current society. Considerations that influence peoples' selection of living arrangement include wheelchair accessibility and availability of support services to assist with personal care and the accomplishment of daily activities.

Most individuals, disabled by SCI, appear to be living in the community as opposed to institutions. DeJong, Branch, & Corcoran's study (1984) of environmental variables in independent living outcomes placed 88% of their sample living in the community. A recent Ontario-based Canadian study (Boschen, 1988), investigating the housing situations of spinal cord injured people, reported that 70% lived in a private house or apartment (many with parents), 19% lived in an apartment project with shared attendant care services, 5% lived in an institution, and the remaining 6% lived in a variety of other accommodations such as housing co-operative, student housing etc. This study did not describe the living arrangement breakdown specifically among those who were quadriplegic. No such information can be found in the literature.

Attendant care may be provided by spouse, other family members, paid attendants, or volunteers (Decker & Schulz, 1985, 1989; Denson, 1987; Smith & Meyer, 1981). Some severely disabled people live in transitional living or group home settings.

Boschen (1988) investigated the perception of choice in housing options among her spinal cord injured sample. Forty-four percent stated that they had no other choices when selecting their current housing and 20% stated that only one other option had existed. The primary reasons cited for poor choices included lack of wheelchair accessibility, long waiting lists, and lack of available attendant care. This study also asked subjects to identify their preferred living arrangement choices. The majority preferred to have their own home or apartment (the first

choice for 80% of the sample) and the least preferred choice was hospital or nursing home.

Living arrangements have been significantly correlated with adjustment measures. Green, Pratt, & Grigsby (1984) determined that the personal self-concept scores of spinal cord injured people were highest for those living with friends, followed by those living with an aide, spouse or other relative. Subjects living in institutions had the lowest personal self-concept scores. Furthermore, this study reported that spinal cord injured people, requiring more assistance in activities of daily living, obtained significantly higher total self-concept scores in comparison to those who needed less assistance. The researchers hypothesized that this result was due to the regular social interaction that occurs from guaranteed contact with care providers each day.

The present study generated information regarding the living situation arrangements of quadriplegic people in Northern Alberta. Since the range of options for independent living appear to have expanded during recent times, the role of specific aspects of living situation in certain outcomes after SCI has become a more fruitful area for research. This study investigated more closely the significance of certain housing and attendant care factors in influencing the dimensions of psychosocial adjustment such as self-esteem, locus of control, and perceptions of control and independence.

CHAPTER III

Methods and Procedures

This chapter details the methods and procedures used to collect the data for this study. The information in presented under the following headings: sample selection, description of the sample, instruments, and data collection procedure.

Sample Selection

The target population to which the results will be generalized is people who are quadriplegic due to SCI living in Alberta. The sample for this research study was drawn randomly from the population of quadriplegic people living in Northern Alberta (specifically living in the band of the province bordered to the South by Red Deer and to the North by Grande Prairie). The names of all potential subjects living in this geographical area were obtained from the file records of the Canadian Paraplegic Association (C.P.A.). Since C.P.A. is involved as an integral component of the Spinal Cord Injury Rehabilitation team in Northern Alberta, the files include the majority of spinal cord injured people. Quadriplegic individuals who may not be included in the population are those who have never had any relationship with C.P.A. which may be the case for people who have relocated into the region without contacting C.P.A. or who were injured prior to the formation of the Alberta Division of C.P.A. Many members

of the latter group are members of C.P.A. The researcher is currently employed by C.P.A. and was granted clearance to use the file records to access all possible subjects for the purposes of this research study.

Two characteristics were used to delimit the population. First, in addition to being quadriplegic due to SCI, individuals had to experience motor paralysis to the extent that they required assistance from another person for some degree of personal care. Two subjects were very nearly independent of requiring personal care assistance but they were included since they had usually required regular assistance and did still require help if they experienced an accident for which they depended on emergency assistance. Second, individuals had to have been injured at least two years. This parameter was imposed since there is empirical support for emotional effects related to recency of injury (Shadish, Hickman, & Arrick, 1981) which could have interfered with overall results.

The population that fulfilled these requirements equalled 150. From this group, a random sample of 80 was drawn. The actual sample equalled 75. Although active efforts were made to contact all 80, three potential subjects declined the request for their participation and two could not be located. There were no obvious similarities between these five subjects to suggest that the resulting sample is skewed with respect to any other measured variable. Since the sample includes 50% of the people living in this geographical region, it is expected to be representative of people who are quadriplegic and living in Alberta.

Description of the Sample

Eighty-one percent of the sample were male and 19% female. In terms of marital status, 29.3% were married, 54.7% were single and never married, 14.7% were divorced, and 1.3% were widowed. In short, 71% were unmarried at the time of data collection. Number of years since onset ranged between 2 and 33 (mean = 10.7, SD = 8.0). Participants' mean current age was 35.5 (SD = 11.4) and mean age at time of injury was 24.7 (SD = 10.2). Eighty-three percent of the sample were under 35 years at time of injury. Detailed information about current age and age at injury is displayed in Table 1.

Table 1

Sample Characteristics: Age at Injury and Current

	Age	
Range	At Injury	Current
0-15	8.0%	0.0%
16-30	69.3	40.0
31-45	17.4	40.0
46-60	5.3	18.7
61+	0.0	1.3

Level of injury ranged from C3-4 to C7 inclusive. Table 2 displays the frequency and percentage of subjects experiencing each level of injury. The most frequent level of injury was C5-6.

Table 2

Sample characteristics: Level of injury

Level	Frequency	Percent
C3-4	4	5.3
C4	3	4.0
C4-5	14	18.7
C5	11	14.7
C5-6	23	30.7
C6	5	6.7
C6-7	12	16.0
C7	3	4.0

Years of completed pre-injury education ranged between 3 and 16, with a mean of 11.2 years (SD=2.4). Twenty-four percent had completed more than a Grade 12 education. Total years of education completed post-injury ranged between 6 and 19 years, with a mean of 12.6 (SD=2.9). There is a small increase in mean years of completed education post-injury.

Both pre-injury and current employment status were recorded. Detailed information is depicted in Table 3.

Table 3

Sample characteristics: Employment status pre-injury and current

Employment status	Pre-injury		Current	
	Freq.	%	Freq.	%
Laborer	21	28.0	-	
Trades	9	12.0		
Professional	2	2.7	13	17.3
Farmer	3	4.0	1	1.7
Student	23	30.7	9	12.0
Homemaker	1	1.3	3	4.0
Other	16	21.3	5	6.7
Retired	-		2	2.7
Unemployed	-		42	56.0

A few aspects of this information are notable. Although no one in this sample was unemployed before injury, 56% were unemployed when data were collected. Pre-injury, 40% of the sample were employed collectively as laborers and tradespeople whereas no one was employed in either area post-injury. These results are unsurprising since most labor and trades jobs require a certain level of physical mobility and manual strength and ability which are all, by definition, impaired for people who are quadriplegic. The increase in frequency of people in the professional category after injury in comparison to pre-injury is optimistic. It appears that some subjects altered their career tracks after injury and some subjects, who were students at time of injury, selected professional career paths after becoming quadriplegic.

Instruments

Individual Data sheet.

The Individual Data sheet (Appendix 1) collected two bodies of information, demographic information and living situation arrangements. The first page asked for demographic details. Specifically, this section requested date of birth, age, gender, marital status, date of injury, years since onset of injury, level of injury, education level completed both pre-injury and current, and employment status pre-injury and current. The subjects filled in blank spaces with this information.

The second page of the Individual Data sheet requested information about living situation. For the five items, the subject selected the one choice that most closely described each aspect of his/her living situation. These items yielded five dichotomous variables. Scores equalled 1 or 2 on each item.

The first item referred to the location of residence. The subject's choices were (a) own home, family home, group home and (b) institution, auxilliary hospital, extended care centre. Group home was included in category (a) because the two local group homes (transitional living facilities) are operated according to a philosophical orientation that emphasizes resident participation in all aspects of the residential setting and resident control over their medical and attendant care needs. Group home was, therefore, deemed to be closer to community-based living situations rather than institutional settings in which control of staffing and living environment management is with the institution.

The second item pertained to staffing arrangement. The subject selected between (a) one primary care provider and (b) staff of care providers. Choice (a) was relevant to people who rely mainly or exclusively on one person to attend to care needs and included those who hire a live-in or visiting attendant, or who are cared for by a family member such as spouse, parent, or sibling. Choice (b) reflected the situation of people who live in group homes, institutions, or who have access to support services programs that offer personal care and other assistance.

Item 3 evaluated whether there was a financial issue with respect to the cost or payment for attendant care service. More specifically, a financial issue was deemed to be present in three circumstances. The first occurred when the person providing the required care is unpaid. The second situation occurred when the person receiving the care has to pay for it from their own resources. In other words, they do not receive any funds designated for attendant care costs. Third, a financial issue was deemed to be present when the funds a person is receiving for attendant care costs were conditional upon them maintaining a low income and marginal assets. This is the case for people who receive funds for attendant care through the Alberta government's Social Allowance program. The funds received will be reduced or eliminated if that person increases his/her income or obtains assets of value. In this case, the conditions of attendant care funds often act as a disincentive to work since secure, ongoing care becomes tenuous (DeJong & Wenker, 1983). Under item 3, if the subject selected one of the first three

choices, a financial issue was determined to be present. The fourth choice represented the absence of a financial issue since care providers were paid for their work and a change in personal income would not interfere with that funding base. This situation was shared by people who use support services programs and those who received funds from the Workers' Compensation Board.

The fourth item measured actual control over attendant care. Subjects were asked to indicate if they had control over the hiring, training, and/or evaluation of care providers, or if they had no control over any of these aspects of staffing.

Item 5 assessed whether or not the living situation was adapted to accommodate the individual's physical needs and wishes. Subjects were asked to indicate if their living environment was adapted completely so that they were able to do everything they could and desired to do. The alternative was that their living environment was partially or not at all adapted for their physical abilities and needs. This item was included because environmental accessibility is essential for people who are quadriplegic who wish to participate in activities of daily living. In an adapted living situation, a quadriplegic person will be able to accomplish the everyday tasks of which he or she is capable. In a non-adapted or inadequately adapted environment, these same tasks become very difficult or impossible to achieve.

Coopersmith Self-Esteem Inventory (CSEI) - Adult Form.

Self-esteem is defined by Coopersmith who designed the CSEI (excerpt in Appendix 2).

> The evaluation a person makes, and customarily maintains, of him- or herself; that is, overall self-esteem is an expression of approval or disapproval, indicating the extent to which a person believes him- or herself capable, successful, significant, and worthy. (Coopersmith, 1984).

The adult version of this inventory consists of 25 statements to which the subject responds with "like me" or "unlike me". Scoring of the form is performed by adding positive items if answered "like me" and negative items if the response is "unlike me". The highest obtainable raw score is 25; the total score is achieved by multiplying the raw score by 4 and, therefore, the highest obtainable total score is 100. High scores correspond with high self-esteem.

Most studies of the test's technical qualities have investigated the School Form of the CSEI. The Adult Form was derived from minor wording changes to make it more suitable to adults. The manual documents adequate to good reliability indices (split-half scores range between .80 and .92; test-retest scores range between .64-.88) for the School Form. Consulting Psychologists Press report that, in the development of norms, the Adult Form Cronbach alpha reliabilities range between .78 and .85 (personal communication, 1990). The validity of the inventory has been investigated by many researchers with different populations. The test manual's review of these studies documents strong predictive, convergent, and construct validity. The School Form has been shown

to correlate highly with personality adjustment and self-concept (Cowan, Altmann, & Pysh, 1978; Dorr, Rummer, & Green, 1976). The Adult Form's construct validity was supported by negative correlations between the CSEI and guilt and anxiety (Ahmed, Valliant, & Swindle, 1985).

Rotter's Internal-External Scale (I-E Scale).

The I-E scale (Appendix 3) is a 29 item forced-choice questionnaire that measures generalized expectancy of control. An internal expectancy or locus of control indicates a belief that one's success and circumstances are contingent on one's own behavior whereas an external locus of control indicates a belief that one's success and circumstances are related to fate, luck, or chance (Rotter, 1966). The test is scored by summing the number of selected responses measuring external expectancy. Since there are six filler items, a score of 23 is the highest obtainable. The higher the score, the more externally oriented the individual.

Rotter (1966) reported extensive evaluations of the I-E scales's reliability and validity. The results of assessments of the measure's internal consistency with a variety of samples range from .65 to .70 and test-retest reliabilities range between .49 and .83. In a study sample of spinal cord injured adult males, internal consistency was .59 (Ferington, 1986). The validity of the scale has been obtained by correlating locus of control with other traits and behaviors such as awareness of environmental features which can affect behavior, achievement motivation, and resistance to subtle suggestion (Rotter, 1966).

Attendant Care Questionnaire.

The Attendant Care Questionnaire (Appendix 4) was developed by the author specifically for use in this study. It consists of 14 items rated on a Likert scale. Subjects indicated the extent to which they perceived themselves to have an impact on their attendant care system and to which they felt independent and free to choose their lifestyle in their current living situation. Two subscale scores are obtained. The first measures perceived control over current attendant care services and over daily life. The second subscale measures perceived independence which is defined as the perception of freedom to choose one's lifestyle, to engage in this chosen lifestyle, and to live on one's own if so choosing. Scores on each scale may range from 7 to 28 with high scores indicating high perceived control and perceived independence.

The questionnaire was pre-tested with five people who are quadriplegic and, as a result, items were altered, eliminated, and added. Content validity was evaluated by obtaining independent ratings of individual item relevance from 4 experts in the field of Independent Living. On a 4-point scale (1-strongly relevant, 2-somewhat relevant, 3-somewhat irrelevant, 4-strongly irrelevant), all except one item received either a 3 or a 4 from all four experts. One item (item 9) was rated as a 2 by one expert.

Test-retest reliablity was evaluated by readministering the questionnaire to a random sub-group of the sample (15 subjects) one month after collecting the data. The test-retest reliabilities were .97 for the subscale measuring perceived

control and .95 for the subscale measuring perceived independence.

Data Collection Procedure

The following procedure was used for collecting the data:

1. Individuals were contacted by the researcher by phone to request their participation in the research. Several points were discussed with each subject. These points included the general purpose of the research, the method by which their name was drawn, the procedure for data collection, the anticipated time commitment required, an explanation of how confidentiality and anonymity were to be assured, and an assurance of the option to decline or discontinue participation at any time. Some subjects asked additional questions which were answered as objectively as possible in order not to reveal inadvertently the hypothesized direction of the results and accidently influence their responses. To subjects who pressed for more information, the researcher explained this rationale for not wishing to influence their responses and offered to speak with them in greater detail upon completion of the study.

2. Upon obtaining each subject's verbal consent to participate, the researcher discussed arrangements for obtaining the data. In-person interviews were requested. Eight subjects preferred to have the questionnaires mailed to them. Consequently, a package containing the consent form, surveys, and a stamped return-addressed envelope were mailed to these individuals. All packages were returned completed. For individuals who agreed to in-person

interviews, arrangements were made to meet at a mutually-agreeable location with the researcher or an assistant. The assistants were all Rehabilitation Counsellors with the Canadian Paraplegic Association who already had established a relationship with each subject prior to the data collection. The assistants had been provided with specific instruction in the procedure of data collection.

3. All in-person interviews were conducted in a standardized manner. The interviewers established rapport initially, which was readily achieved since the interviewer already had a working relationship with each subject. The general purpose of the research was restated. The subject read and signed the consent form (Appendix 5).

4. The surveys were completed by the subject in the following order:

Individual Data sheet

Coopersmith Self-Esteem Inventory - Adult Form

Rotter Internal-External Scale

Attendant Care Questionnaire

All questionnaires were coded with an identification (ID) number to ensure that each individual's identity remained anonymous.

5. Upon completion of all surveys, the subject was thanked for his/her time, assistance, and cooperation. Many individuals were physically unable to complete the forms or preferred not to write them independently. These subjects were offered the choice to have the interviewer or another person record their selected responses. All such subjects selected the interviewer. The subject read

the surveys and spoke aloud their response to each item. Two subjects needed the items read to them since they were unable to read at the time of the interview (both were lying prone in bed).

The time taken to complete the set of questionnaires ranged from one half hour to one hour. Many subjects were interested in discussing aspects of the questionnaires after the interview.

CHAPTER IV

Results

This chapter reviews the results obtained from the research data. The results are organized according to method of analysis in the following order: descriptive statistics, correlational analysis, regression analysis, and comparisons between groups of people in different living situations.

Descriptive Statistics

The means, standard deviations, and ranges of the continuous variables are shown in Table 4. Findings are within expected ranges. Self-esteem scores for this study's respondents are comparable to the norms (t = 1.42) reported by Consulting Psychologists Press Inc. (personal communication, 1990). Locus of control scores are within the mean range (6.06-10) reported by Rotter (1966) and are very similar to those obtained with a sample of spinal cord injured subjects (Ferington, 1986) for which the mean was 8.63 (SD = 3.33).

Table 4

Means, Standard Deviations, and Ranges of Continuous Variables

Variable	Mean	Standard deviation	Range
Self-esteem	73.52	18.47	28-100
Locus of control	8.88	3.62	2- 18
Perceived control	23.05	3.02	15- 28
Perceived independence	19.41	2.73	13- 26

The frequencies and percentage of subjects living under the various aspects of living arrangements are displayed in Table 5.

Table 5

Frequencies and Percentage of Subjects According to Characteristics of Living Situation

Characteristic	Total Sample N=75		Community Sample N=69	
	Freq.	%	Freq.	%
1. Location				
(a) Community	69	92.0	69	100.0
(b) Institution	6	8.0	0	0.0
2. Care Provider				
(a) One primary attendant	48	64.0	48	69.6
(b) Staff	27	36.0	21	30.4
3. Finances for Care				
(a) Financial issue	41	54.7	41	59.4
(b) No financial issue	34	45.3	28	40.6
4. Control over Staffing				
(a) Actual control	67	89.3	67	97.1
(b) No control	8	10.7	2	2.9
5. Adapted living environment				
(a) Adapted	44	58.7	40	58.0
(b) Not adapted	31	41.3	29	42.0

A significant majority of the subjects lived in community-based settings (92%) including own home, family home, or group (transitional) home. Nearly two-thirds of the sample relied on a single primary care provider. Fifty-five percent of the subjects reported that their care providers were not paid or that their finances for attendant care were contingent on them maintaining a low income. In terms of actual control, nearly 90% reported that they did control some or all aspects of the hiring, training, and evaluation of their care providers. Finally, three-fifths of the subjects described their living environment as adequately adapted for their needs and abilities.

Table 5 also presents frequencies and percentage of the segment of the sample that lived in community-based (as opposed to institutional) settings. In comparison to the frequencies among the total sample, a few differences are notable. A greater percentage of the subjects living in the community were reliant on a single primary care provider (nearly 70%) and did not have secure funding to pay for attendant care (60%). Nearly the entire group of people living in the community reported having actual control over the hiring, training, and/or evaluation of their care providers.

Correlational analysis

Two separate correlational analyses were conducted. The first examined intercorrelations between all variables for the entire sample. The second analysis examined the intercorrelations between all variables for people who lived only in

community settings. The major correlates of self-esteem and locus of control are shown in Table 6. The major correlates of perceived control over attendant care and perceived independence are displayed in Table 7. Significant results will be discussed as they correlate with the variables of self-esteem, locus of control, perceived control over attendant care, and perceived independence in current living situation.

Table 6

Major Correlates of Self-Esteem and Locus of Control

Self-Esteem	r	r*	Locus of Control	r	r*
Perceived control	.43	.43	Perceived independence	-.44	-.46
Perceived independence	.37	.37	Perceived control	-.27	-.24
Locus of control	-.34	-.35	Gender	.29	.27
Current education	.30	.30	Level of injury	-.20	-.19
			Adapted environment	.18	.21

r* refers to subsample of subjects living in community. For correlations greater than .20, $p<.05$; .27, $p<.01$; .29, $p<.005$; .34, $p<.001$.

Self-esteem.

Some statistically significant correlations were obtained between self-esteem and other variables. These correlations were observed among both the total sample and among the sample living in the community. Self-esteem correlated negatively with external locus of control ($r=-.35$, $p<.001$). This result is consistent with other studies which have obtained similar correlations between

locus of control and other adjustment measures (Ferington, 1986; Mazzulla, 1984). The lower the IE scale score (the more internal the locus of control orientation), the greater the probability that the self-esteem score will be higher. Significant positive correlations were obtained between self-esteem and perceived control over attendant care and perceived independence in current living situation ($r = .43$, $p < .001$ and $r = .37$, $p < .001$ respectively). Higher perceived control and perceived independence scores were correlated with higher self-esteem scores. There was also a significant correlation between self-esteem and current education level ($r = .30$, $p < .005$). Subjects who had achieved higher current levels of education tended to have higher self-esteem scores.

Several hypotheses were not supported by the results. Living in a community-based as opposed to an institutional environment was not correlated with self-esteem. Having access to a staff of care providers as opposed to a single primary attendant was not correlated with self-esteem. Furthermore, the absence of a financial issue related to attendant care costs, actual control over attendant care, and adapted living environment were not significantly correlated with self-esteem. In short, the isolated aspects of the living environment failed to correlate with self-esteem.

Locus of control.

Locus of control correlated negatively with perceived control over attendant care and perceived independence in the current living situation ($r = -.27$, $p < .01$ and $r = -.44$, $p < .001$, respectively). The more internal the locus of control

orientation, the greater the probability that perceived control and perceived independence were high.

In terms of living situation characteristics, living in a fully adapted living environment correlated with locus of control ($r = .21$, $p < .05$). The more internal the expectancy of control, the greater the probability of living in a fully adapted environment. Since these results are correlational, the alternate explanation may also be true. People living in an adapted living situation appear to be more likely to have an internal locus of control. The other hypotheses failed to receive support from the results. No significant correlations were obtained between locus of control and other variables measuring aspects of the living situation including home vs. institution, one primary attendant vs. staffing system, presence or absence of a financial issue related to attendant care costs, and actual control over attendant care.

Two other statistically significant correlations were observed with locus of control. A positive correlation was obtained between gender and locus of control ($r = .29$, $p < .005$). That is, males in this sample tended to have more internal orientations. A negative correlation between locus of control and level of injury ($r = -.20$, $p < .05$) indicated that the more severe the disability the more external the locus of control expectancy. Although statistically significant, this correlation is small. The same correlation computed for the sample living in community-based environments was not significant, although it was only .01 lower than that for the entire sample.

Table 7

Major Correlates of Perceived Control and Perceived Independence

Perceived Control	r	r*	Perceived Independence	r	r*
Perceived independence	.50	.49	Adapted environment	-.30	-.31
Location	-.37	-	Years since onset	.24	.26
Actual control	-.35	-.08	Level of injury	.22	.22
Current education	.31	.28	Age at injury	-.21	-.15
Age at injury	-.24	-.14	Gender	-.20	-.19
Adapted environment	-.20	-.28			

"r*" refers to subsample of subjects living in community settings.
For correlations greater than .20, $p<.05$; .27, $p<.01$; .29, $p<.005$; .34, $p<.001$.

Perceived control.

Perceived control over attendant care services was significantly correlated with a few predictor variables. Perceived control and perceived independence in current living situation were correlated ($r=.50$, $p<.001$). A high degree of perceived control indicated a high probability of perceived independence. Furthermore, perceived control over attendant services was negatively correlated with living location ($r=-.37$, $p<.001$). People living in community-based settings tended to report higher perceived control than people living in institutions. Similarly, perceived control correlated significantly with actual control ($r=-.35$, $p<.001$). Furthermore, perceived control and environmental accessibility were significantly correlated ($r=-.20$, $p<.05$). People living in fully adapted housing reported higher perceived control than those living in inadequately adapted

environments.

Other significant correlations were observed. For the entire sample, age at injury correlated negatively with perceived control ($r=-.24$, $p<.05$). People injured at younger ages tended to report higher perceived control than those who were older. Current level of education also correlated with perceived control ($r=.31$, $p<.005$). People with more years education tended to have greater perceptions of control over their attendant care and current lifestyle.

Perceived independence.

Perceived independence in current living situation correlated significantly with a few predictor variables. In terms of the hypotheses, perceived independence correlated significantly with environmental accessibility of the living situation ($r=-.30$, $p<.005$). Living in a fully adapted environment was associated with the probability of a higher perceived independence score. None of the other hypotheses were supported by the results. Significant correlations were not obtained between perceived independence and location of accommodation (community-based vs. institution), staffing arrangement (one primary attendant vs. staffing system), presence or absence of a financial issue related to attendant care expense, or actual control over attendant care.

Other significant correlations were noted. For the entire sample, age at injury correlated negatively with perceived independence ($r=-.21$, $p<.05$). People who were younger at time of injury reported higher perceived independence. Years since injury also correlated significantly with perceived independence

($r = .24$, $p < .05$) as did level of injury ($r = .22$, $p < .05$). People who had been injured longer and those with less severe disability indicated higher perceived independence scores. Gender also correlated with perceived independence ($r = -.20$, $p < .05$) with males tending to have higher scores. No other significant correlations were obtained.

Other significant correlations.

Location of accommodation correlated significantly with a few other variables. Living in the community was related to tendency to have a single primary attendant ($r = .39$, $p < .001$). Current age and age at injury correlated with living location ($r = .27$, $p < .01$ and $r = .29$, $p < .005$ respectively). People residing in institutions tended to be older now and to have been older at time of injury.

Staffing arrangement correlated with a few variables. Having a single care provider was related to a financial issue whereas having access to a staff of attendants correlated with the absence of a financial issue ($r = .49$, $p < .001$). Furthermore, more people with staff care reported no actual control over attendant care. This result was expected since people in institutions lacked actual control.

The presence of a financial issue correlated with actual control over attendant care ($r = .38$, $p < .001$). People whose attendant was unpaid, or whose funding for attendant care was contingent on low income tended to have more actual control over their staff. This result may be an artifact because all except two subjects who reported not having actual control over attendant care resided in

institutions.

Actual control correlated positively with current age and age at injury ($r=.26$, $p<.05$ and $r=.36$, $p<.001$). People who were older at time of data collection and at injury tended to have less actual control over attendant care. This result is really no different than the similar correlations noted with location since, with the exception of two subjects, people who reported no control lived in institutional settings.

Regression Analysis

Findings from the stepwise multiple regression analysis are presented in Table 8.

Table 8

Stepwise Regression Analysis on Self-Esteem

Variable	Correlation Coefficient (r)	Stepwise Multiple Correlation (R)	Stepwise R^2	R^2 Increment
Perceived control	.43	.43	.18	
Locus of control	-.35	.49	.24	.06

$p<.05$

Perceived control over attendant care and locus of control were the only

predictor variables that contributed significantly to the measure of self-esteem ($p<.05$). In short, 24% of the variance in self-esteem scores was explained by these two variables. Entering all other predictor variables into the equation added 5% to the explanation of variance but no single variable contributed significantly.

Comparison of Groups

Although a comparison between groups was not intended for this study, information regarding numbers living with various attendant care arrangements was gathered in the event that it proved useful. Frequencies and percentage of subjects residing under each circumstance are presented in Table 9.

People who are quadriplegic are living under a variety of circumstances by which their personal care needs are provided. In this sample, the largest group (26.7%) hired a live-in attendant to provide personal and other care. The second largest group (20%) were cared for by their spouse, of which 6 were financially remunerated for this work and 9 were not. The third largest group (14.7%) used a combination of hired and family help to have personal care needs met and 13.3% of the sample only used the services of an established Support Services program.

Since discernible groups were identified, comparisons were made to determine if there were significant differences between them on the variables of self-esteem, locus of control, perceived control, and perceived independence. The

groups compared were differentiated by attendant care system used and included the following: spouse, family member, support services program, live-in attendant, and combination of care providers.

Table 9

Frequencies and Percentage of Subjects According to Living Arrangement

Living Arrangement	Frequency	%
Own Home		
Spouse as Care Provider		
Paid	6	8.0
Unpaid	9	12.0
Family Member as Care Provider		
Paid	3	4.0
Unpaid	4	5.3
Support Services Program	10	13.3
Live-in Attendant	20	26.7
Visiting Attendant	3	4.0
Combination of Above	11	14.7
Group Home/ Transitional Living	3	4.0
Extended Care Center	6	8.0

Initially, groups were compared on demographic variables to ensure that they were not different for other reasons. No significant differences were

obtained on the basis of sex, age, age at injury, years since injury onset, level of injury, education level pre-injury, and current education level. Marital status was different between groups wherein subjects who were married tended to have their spouse as primary care provider. Consequently, it was established that there was no need to control for other factors when comparing groups.

Analysis of variance was conducted to compare differences between groups on the variables of self-esteem, locus of control, perceived control over attendant care, and perceived independence in current living situation. No significant differences were found between groups for any of these variables at the $p = .05$ level. These results failed to reject the null hypothesis that there were no significant differences between groups according to living arrangement.

This analysis was limited. The group sizes varied considerably and were not large enough to warrant a good analysis.

CHAPTER V

Discussion

This chapter will explain the results obtained in this research study. The discussion will address the data as they pertain to the following areas: self-esteem, control, independence, living situation arrangements, the role of demographic variables, Trieschmann's model, and explanations for unsupported hypotheses.

Self-Esteem

In general, the quadriplegic subjects in this study reported a high level of self-esteem. In spite of serious physical disability, most of the participants appeared to have a perception of themselves as worthy, competent, and capable. Since this was a random sample of subjects, the results suggest that people sustaining severe SCI do appear to adjust to the psychological trauma of disability and to maintain and develop positive views of themselves. These data confirm those of previously cited research yielding similar findings (Green, Pratt, & Grigsby, 1984).

These results are significant considering that many authors have postulated that people with physical disabilities are stigmatized and occupy a devalued status in our society (DeLoach & Greer, 1981; Wright, 1983). It has been suggested that self-devaluation derives from the inability to perform the ordinary tasks that most

people take for granted, such as toileting, dressing, moving around, and feeding. Dependency for such basic activities of daily living which are normally associated with infancy are expected to generate feelings of inferiority and personal devaluation (Vash, 1981). Assuming that spinal cord injured people would internalize this societal view, it is expected that they would experience feelings of inadequacy and low self-esteem. The results of this study fail to support this postulate. The generally positive self-concept of these people may indicate that people with SCI do reassess and rebuild their identity and eventually attain a more positive view of themselves as proposed by Vash's (1981) concept of transcendence, or growth through adversity. As she explains, people experiencing the dependency imposed by spinal cord injury may eventually take the opportunity to develop more psychological maturity as material priorities are replaced by social and spiritual values.

Self-esteem among this sample of quadriplegic subjects was significantly related to several factors, particularly locus of control and perceived control over attendant care arrangements. The negative correlation between external locus of control and self-esteem confirms similar findings in other studies which have linked the presence of an internal locus of control with various measures of subjective well-being (Ferington, 1986; Mazzulla, 1984; Swenson, 1976) within samples of spinal cord injured subjects. Furthermore, this study demonstrated that locus of control was a significant predictor of self-esteem. That is, spinal cord injured people with an internal locus of control are more likely to have

higher self-esteem.

Perceived control over attendant care system was a more powerful variable than locus of control in simple correlation and prediction of self-esteem. People who reported higher levels of self-esteem also had stronger perceptions of control over their personal care and staffing needs. Furthermore, the higher the perceived control, the stronger the prediction of positive self-esteem. The correlational nature of the analysis does not permit an inference of causality. Thus whether these associations represent the therapeutic value of the perception of control over attendant care on development of positive self-esteem or, conversely, reflect the likelihood of people with high self-esteem deliberately arranging for control over their attendant care cannot be ascertained. Both relationships may be operating. The latter seems intuitively true. However, it is also possible that the former holds some validity in the case of people whose living circumstances require them to assume control. Regardless, the various aspects of control are operating significantly in the relationship.

Importance of Control

These results illustrate the importance of the variable of control in the well-being of people who are quadriplegic. It would appear that the Independent Living movement's emphasis on control has not been misplaced. As the philosophy and tenets of the movement expound, if society and the environment provide the opportunity for disabled people to experience control over their

personal needs, their sense of competence and self-esteem will ensue. The movement has focused on efforts to alter the environment in order to facilitate this sense of control and to assist disabled people in ultimately assuming responsibility for ensuring that their needs are met.

Furthermore, certain environmental variables examined in this study were significant correlates of the control measures. Living in an adapted environment recurred as a correlate with locus of control and perceived control and was more significant among the sample of subjects residing in community-based settings. The more architecturally suitable the living environment, the greater the perception of control within that environment. However, the frequencies of people living in fully versus inadequately adapted living situations (Table 5) showed that little more than half the subjects were living in environments sufficiently adapted to permit them to function as fully as possible. Since the research design was correlational, it cannot be determined if lack of adapted design preceded lower levels of perceived control or if people who have lower perceptions of control failed to ensure that their environments are fully adapted for their needs. It would be valuable to investigate if spinal cord injured people with lower levels of perceived control would experience a change in this variable if their living environment offered more opportunity for independent functioning.

People living in community settings reported significantly higher levels of perceived control than those living in institutions. This result was unsurprising and corroborated by the other evidence that people residing in institutions lack

actual control over the hiring and evaluation of staff who provide the personal and other care.

Interpretation of these results must bear in mind that the "control" being measured is over attendant care system. People vary in their preference for control (Ferington, 1986) and may, therefore, react to control differently when they are expected to take it. Ferington (1986) determined that people who preferred control demonstrated more effective coping when they had it. We still do not know how people, who prefer not to have control, cope when they are expected to be in control. This may explain the absence of a significant relationship between living environment (community versus institution) and self-esteem. Perhaps people living in institutions prefer not to have control and, therefore, their self-worth and well-being are unaffected by the lack of control. Alternatively, people living in institutions understand that they have less control but this does not affect their self-esteem.

Independence

The variable measuring perceived independence (defined as perception of choice in one's living arrangement and one's daily activities) showed some significant relationships with other measured variables. Of primary note, perceived independence and perceived control were strongly related. There is a tendency for quadriplegic people who report control to also report greater independence. Furthermore, people with an internal locus of control also tended

to have higher levels of perceived independence. These strong relationships are unsurprising since control and independence, as defined here, are closely linked concepts as they both presume self-determination and self-reliance.

Perceived independence correlated significantly with self-esteem suggesting that people who felt that they have choices in how and where they live generally felt more positively about themselves. Of the environmental characteristics, living in an adapted environment proved to be a fairly strong correlate of perceived independence. As with perceived control, these results do not reveal if independent people ensure that their living environments are adapted or if living in such a situation fosters the sense of independence. In support of the first possibility, Nosek, Parker, and Larsen (1987) noted that psychological factors, specifically certain personality traits, were characteristic of psychologically and socially independent people. However, the question still remains whether access to a suitably supported and adapted living environment would facilitate a stronger sense of independence and control for those people who are not as psychologically and socially independent. Perhaps, there is a more complex interaction involved. As Trieschmann (1988) has summarized "psychological and social independence derive from access to environmental resources, whereas overcoming the societal barriers to environmental resources derives from psychological and social independence" (p.225). It is not unreasonable to assume that different people respond differently to different circumstances.

Consequently, it seems reasonable to expect that, if people who are

quadriplegic are living in appropriately designed settings, explanations of their perceived independence and control could then derive from psychological and social factors. The number of environmental variables causing frustration and hampering independent, productive behavior could be reduced. After all, of all factors, environmental variables can be more easily changed through policy and programming. Organic characteristics such as age, sex, level of injury cannot be changed. Other individual characteristics, such as functional independence and personality variables, are likely only subject to minor modification through programs and therapy. In contrast, environmental variables, such as housing and attendant care, can be changed through legislation and programs.

This analysis did not permit an evaluation of the influence of an adapted environment on other outcome measures. Future research could compare the adjustment of people living in fully adapted versus partially adapted accommodation who also vary along other psychosocial dimensions such as psychological independence or locus of control. For example, are people with an internal locus of control more likely to choose fully adapted accommodation? Furthermore, what factors shape an individual's eventual living arrangements? DeJong, Branch, and Corcoran (1984) determined that factors such as marital status, age at injury onset, and availability of transportation were salient. Although this information is valuable, it does not inform us how people choose or come to live under their particular circumstances. A more qualitative research design would allow for a deeper analysis of this process. Another research

question raised by this study is whether or not, for people with an external locus of control, living in a fully adapted environment encourages the development of a stronger sense of independence and/or a more internal expectancy of control.

Living situation arrangements

Housing and attendant care are two of the fundamental issues associated with the Independent Living movement (DeJong & Wenker, 1983; Wiggins, 1983). In the case of severely disabled people who require support services, both issues are critical and relevant to the development of a self-reliant lifestyle. As the results illustrate, in Northern Alberta, people who are quadriplegic are living under a variety of housing and attendant care circumstances. Most people live in the community instead of institutions. All have established some attendant care system.

As is apparent from the results, there is no single solution to the challenge of meeting the housing needs of people who need support services. Obviously, resources that offer housing, attendant care, and funding for attendant care are available to the majority of people with SCI. However, nearly one-fifth of this sample relied on unpaid family members to provide their care (Table 9). The frequency of family members being primary care provider raises questions regarding the effect of this role on the quality and nature of family relationships, and on general family functioning. Decker & Schulz (1989) investigated the determinants of well-being among the significant others of spinal cord injured

people (the majority were spouses). They reported that as the significant other spent more time per day providing assistance to the individual in all areas including activities of daily living and as they perceived more burden caring for the individual, they experienced a lower level of life satisfaction and more depression. McGowan & Roth (1987) have reported a negligible impact of functional independence on perceived family functioning but have also determined that duration of disability is associated with a decline in family functioning. Their sample included subjects with all levels of SCI and did not specifically investigate long-term family functioning in families where care provision is one member's chronic responsibility. This topic remains fertile ground for future investigation.

Although more descriptive in nature, several interesting results emerged from the data analysis regarding features of the living arrangements. Most people living in the community rely on a single primary attendant to provide personal and other care (70%). Furthermore, there was a strong correlation between the presence of a financial issue and reliance on a single care provider. The facts, that most quadriplegic individuals rely on a single person and do not have secure access to funds to pay for this care, yield speculation about the pressure to maintain reliable care, and the disincentives to secure employment that may affect income eligibility. Evidence regarding these two unexamined issues could be obtained through more detailed interviews with disabled people and their care providers regarding the nature, benefits, and stresses of the relationship. In order to assess the possible effects of the financial issue as a disincentive to seek

income-generating employment, the criterion variable measuring productivity, such as that developed by DeJong and Hughes (1982), would be more useful. When used with a sample of spinal cord injured people, economic disincentives were determined to be a significant predictor of productivity (DeJong, Branch, & Corcoran, 1984). The economic disincentives that they measured did not include attendant care funds that are conditional upon maintaining a low income, but other circumstances such as pension and long-term disability income that are only secure as long as a person is incapable of any gainful employment.

Role of Demographic Variables

Some significant correlations involving demographic and personal characteristics must be noted. These include age, level of injury, and educational level.

Age.

People living in the community tend to be younger now and to have been younger at the time of injury. Older quadriplegic people appear to be more likely to be institutionalized. The reasons for this situation are unclear. Perhaps there is a tendency for older subjects to resign themselves to their disability and its limitations rather than to invest energy into coping with the challenges. It may be that people older at injury believe that they have lived long enough and, therefore, they do not see the point in trying to adjust to such a drastic change. It may also be possible that older people are less encouraged to seek independent

living options by rehabilitation and health professionals. Therefore, these people may be unfamiliar with other living situation choices. Furthermore, there is perhaps a need for other living arrangements (i.e., less institutional but with plenty support systems) that would meet the needs of older people. Further study may uncover the nature of this issue more specifically.

This result contrasts with that obtained by DeJong, Branch, & Corcoran (1984) which found age at injury onset to be significantly related to residential arrangement. Their results determined that people who were older at injury tended to have achieved more independent living situations. A few possibilities are offered as explanations for these contrasting results. This study's sample consisted only of quadriplegic spinal cord injured people whereas their study included subjects with all levels of spinal injury. For people with lower lesion SCI, living independently in the community is more easily achieved since dependency on others to survive is less probable. Furthermore, most older people who sustain SCI are quadriplegic (Stover & Fine, 1986; Young, Burns, Bowen, & McCutcheon, 1982). Since quadriplegics need attendant care assistance, it may be easier to arrange for institutional care rather than community-based care.

Age at injury was also related significantly with perceived control indicating that people who were younger at the time of injury tended to experience more control over their attendant care arrangements. Since this result failed to reach significance among the sub-sample living in the community, it would seem to derive from the evidence that people older at injury are more likely to be residing

in institutional settings.

Level of injury.

As with results obtained in other research (Decker & Schulz, 1985; Ferington, 1986), level of spinal injury did not correlate with perceived control. Even though people with more severe disability have less physical control over their bodies and their self-care, they do not necessarily experience less control over the quality and nature of care that they receive. Severity of disability, and its concomitant absence of physical control, do not appear to bear significant impact on degree of perceived and personal control over one's immediate circumstances.

Contrary to previous research (Swenson, 1976), these results noted a significant (although small) relationship between level of injury and locus of control. Without wanting to exaggerate the significance of this result, it may suggest that, when considering very severe disability, locus of control is affected. People with high spinal cord lesions experience complete physical dependency, and may be extraordinarily challenged to establish or maintain internal beliefs of personal control over their circumstances and existence. Previous studies have included all levels of SCI and have tended to compare paraplegia and quadriplegia, rather than specifically isolating the levels of spinal lesions causing quadriplegia as investigated here.

Educational level.

Current level of completed education was an important factor in self-esteem and perceived control over attendant care among respondents in this

study. Higher levels of completed education were positively correlated with self-esteem and with perceptions of control over attendant care and living circumstances. As with all correlational results, no causal explanation can be made since people with positive self-esteem are likely to pursue higher education. However, achieving higher education will probably increase self-esteem. Longitudinal research or comparison of matched groups would permit a better analysis of this relationship.

Trieschmann's Model Revisited

This study has attempted to determine if certain environmental and psychosocial characteristics contribute to the self-esteem, perceived control, and perceived independence of people disabled by high lesion spinal cord injuries. Trieschmann's systems approach, which assumes that the long-term outcome of disability involves a continuing adjustment of the balance between characteristics of the person and the environment, was used as a theoretical basis for the development of the studied hypotheses. The results have provided some limited support for the premises of this model.

Although the relationships between self-esteem and characteristics of the living situation were nonsignificant, the other measured psychological variables (locus of control, perceived control, and perceived independence) yielded some significant relationships with these environmental variables. Since these other psychosocial variables were significant in the prediction of self-esteem, there

appears to be some interaction between the classes of variables in explaining self-esteem. In short, although the evidence presented by this study does not strongly indicate the role of living situation arrangements in self-esteem of people who are quadriplegic, it does provide some support for the systems view postulated by Trieschmann (1988).

There has been a gentle debate discussed in the literature arguing the relative importance of psychosocial and environmental variables in the outcomes of severely disabled people. DeJong (1979) has emphasized the Independent Living position that the environment poses the primary obstacles to productivity and independent living. Nosek, Parker, and Larsen (1987) have claimed that the individual is ultimately responsible for changing in order to adjust to the challenges of disability. Since both perspectives have secured some empirical support, the conclusion that both are valid seems reasonable. The correlational nature of this study permits the consideration that both these perspectives offer reasonable explanations of the results and, given differences along other continuums, individual differences may be accounted for by psychosocial and environmental variables. In short, the specific aspects of the organic, psychosocial, and environmental classes of variables can only be analyzed for discussion purposes, since the whole system accounts for more than the sum of its parts.

Explanations for Unsupported Hypotheses

The hypotheses regarding the correlations between aspects of the living situation and self-esteem failed to be significant. Furthermore, only 24% of the variance in self-esteem scores was accounted for by the measured variables. Several possible explanations are offered for these findings. The immediate explanation is that significant relationships do not exist between self-esteem and the aspects of the living situation studied here (namely location, staffing arrangement, financial issue, actual control over attendant care, and adapted livng environment). Self-esteem may be a generally more stable construct and less sensitive to external variables.

However, methodological explanations seem plausible. Self-esteem may not be an adequate or appropriate measure of adjustment. An alternative indicator, productivity, has been used as an outcome measure in a few other publications (DeJong, Branch, & Corcoran, 1984; Kemp & Vash, 1971). The concept addresses a person's overall contribution to personal, family, and community life by measuring participation in gainful employment, homemaking, school or educational programs, formal organizations, and leisure time activities (DeJong & Hughes, 1982). This concept is the Independent Living movement's justification for the removal of environmental barriers and the introduction of new services. In this study, more significant relationships may have been observed between the studied aspects of the living situation and productivity than were obtained with self-esteem.

A third explanation for failure to obtain significant results could be due to the uncertain validity of the Coopersmith inventory as a measure of self-esteem with this sample. Although the School Form has been extensively validated and widely used as a clinical and research tool, the Adult Form does not yet have such extensive support in the published literature.

A fourth possible explanation may be that some of the living situation predictor variables collapsed too many qualitatively different situations together. For example, the variable assessing the presence of a financial issue included people cared for by unpaid spouses and live-in attendants among others. In many cases where the spouse is care provider, both partners are gainfully employed. Therefore, even though there is no back-up funding for attendant or relief care, there is likely an adequate family income to cover expenses. This circumstance is different from that of the individual dependent on government assistance which will decrease or cease when they begin earning an income, particularly since it is challenging to earn enough to support oneself and an attendant's wages.

Having observed the possibility of this explanation, the data were re-evaluated by comparing groups according to the attendant care arrangement. For this sample, although there were differences in mean scores, these failed to reach significance because the groups' variances differed considerably. The sample size and individual group sizes need to be larger in order to fairly test differences between groups.

CHAPTER VI

Summary, Conclusions, Limitations, and Implications

This final chapter will summarize all aspects of this study. The summary will include descriptions of the problem, the method, and the results. The study's primary conclusions and limitations will be reviewed. Finally, implications for future study and practise will be discussed.

Summary

The problem.

The general problem investigated by this study is adjustment to SCI and the role of environmental variables in this process. This field has been examined from many perspectives. Among these have been a focus on the stages of adjustment (Bracken, Shepard, & Webb, 1981; Hohmann, 1975; Kerr & Thompson, 1972; Livneh, 1986; Stewart, 1977-78), and the personality characteristics of people who adjust successfully (Kemp & Vash, 1971; Malec, 1985). Incorporating some of these ideas, Trieschmann (1980, 1988) has presented a multi-variable model of adjustment to SCI which assumes an ongoing process that involves the interaction of organic, psychosocial, and environmental variables. Environmental variables have been identified by the Independent Living movement as the primary source of problems confronting disabled people.

This perspective postulates that independent living can be achieved if disabled people are able to control their lives and to choose their lifestyle by having access to alternatives in living circumstances that minimize their dependence on other people.

The primary purpose of this study was to investigate the significance and role of specific psychosocial variables (locus of control, perceived control over attendant care, and perceived independence in the current living situation) and specific aspects of living situations (housing and attendant care) in the self-esteem of people who are quadriplegic due to SCI. The characteristics of living environments included the following: location (community or institution), staffing arrangement (one primary attendant or staff of care providers), the presence or absence of a financial issue related to attendant care costs, actual control over the hiring, training, and evaluation of staff, and degree of architectural adaptation of the living environment.

Method.

This study used correlational method to analyze the relationships between measured variables. The sample, numbering 75, was randomly selected from the Northern Alberta population of quadriplegic people, who have been disabled for a minimum of 2 years. Comparison of the demographic characteristics of the sample with United States national statistics indicate that the study sample was representative.

Four instruments were used to collect the data. Using the Individual Data sheet, basic demographic information and specific characteristics of the housing and attendant care situation were obtained. The Coopersmith Self-Esteem Inventory yielded a measure of self-esteem. To measure locus of control, the Rotter Internal-External scale was used. Finally, the scores for perceived control over attendant care services and perceived independence in the current living situation were obtained from the Attendant Care Questionnaire, developed specifically for this study.

The data were collected through personal interviews with each subject (with a few exceptions who completed the surveys independently and mailed them to the researcher). Data collection time averaged between one-half to one hour with each subject.

Results.

Several statistical methods were conducted during the data analysis. Descriptive statistics (including means, standard deviations, and ranges) from the questionnaires and the frequencies of subjects living with the various attendant care and housing characteristics were obtained. The overall descriptive results indicate that, generally, the self-esteem among participants in this study is strong. Locus of control results are consistent with those obtained in other studies (Ferington, 1986) and indicate an average tendency towards an internal expectancy of control.

The correlational analysis yielded several statistically significant correlations. Most notably, self-esteem correlated with an internal locus of control, perceived control over attendant care, perceived independence in the current living situation, and current level of achieved education. None of the living situation characteristics correlated significantly with self-esteem. Locus of control expectancy was significantly correlated with perceived independence and perceived control. Furthermore, one living situation characteristic, living in a fully adapted environment, had a significant correlation with an internal locus of control.

Perceived control correlated significantly with three living situation characteristics: location, actual control over attendant care, and adapted environment. Residing in the community, having control over attendant care, and living in fully adapted accommodation increased the probability of experiencing control over personal care and living circumstances. Perceived independence also correlated significantly with adapted living environment indicating that living in fully modified accommodation is associated with stronger perceptions of choice in how and where one lives.

The regression analysis results indicated that only two variables, perceived control over attendant care and locus of control, were statistically significant predictors and accounted for 24% of the variance in self-esteem scores. No living situation factors contributed significantly to self-esteem scores.

Comparison between groups, differing according to attendant care

arrangement, failed to detect significant differences in self-esteem, locus of control, perceived control, and perceived independence.

Other signficant correlations were obtained with certain demographic variables. Current age and age at injury were related to living location. People who were older and who had been older at the time of injury were more likely to be living in institutional settings. Level of injury was correlated (slightly) with locus of control and perceived independence which suggests that spinal cord injured people with more severe disability experience a slightly weaker sense of control and somewhat less choice over their circumstances and their lives. Completed education level was a significant correlate of self-esteem and perceived control. Those with more education tended to have stronger self-esteem and sense of control.

Conclusions

Certain conclusions can be drawn from these results. First, as measured by the Coopersmith Self-Esteem Inventory, self-esteem among the quadriplegic participants in this study appears to be strong. Although these individuals have all experienced major physical trauma and its concomitant effects on all aspects of life, they seem, on average, to have been able to maintain or develop positive views of themselves as competent, capable, and worthy.

A second conclusion generated from the correlational and regression analyses suggests the significance of control in the sense of well-being of people

who are quadriplegic. Both locus of control and perceived control over attendant care services figured as significant correlates and predictors of self-esteem. Obviously, a causal relationship cannot be concluded. However, the significance of the role of control supports the Independent Living movement's emphasis on removing barriers and creating alternatives that enhance the control experienced by people with disabilities.

Third, people who are disabled by quadriplegia, are living under a variety of circumstances. The large majority are living in community-based environments. Most rely on a single primary attendant and most have rather insecure or no access to financial resources specifically to cover the expense of attendant care. Regardless, for the most part, these individuals report having control over their attendant care system and having choices in how and where they live.

In spite of undetected relationships between self-esteem and aspects of living environments, some of these environmental variables did correlate significantly with perceived control and perceived independence. Living in a fully adapted environment recurred as a salient correlate of both these variables. Living in a community-based setting was also a significant variable with perceived control. Conclusions regarding which variable preceded the other cannot be drawn but, considered in the light of other research data (DeJong, Branch, & Corcoran, 1984; Nosek, Parker, & Larsen, 1987), both possibilities may be important.

Limitations

This study has several limitations which must be considered when interpreting the findings. The design is correlational and, consequently, no conclusions regarding cause and effect relationships can be made. Although use of multiple regression analysis permits conclusions about variables that predict certain outcomes, it does not explain causal significance.

The sample was too small to permit adequate comparisons between groups, particularly since several groups were discernible. In order to increase sample size significantly, a larger geographical area would have to be represented. Related to sampling, a strength of this study was the randomness by which participants were selected. As a result, the sample is representative and the probability of confounding variables that bias the direction of results is reduced.

The instruments and measures must also be considered when evaluating the results. The Coopersmith Self-Esteem Inventory (Adult form) has not been widely used in research settings and its construct validity has not been fully investigated in the published literature. Although the Attendant Care Questionnaire's content validity and reliability were evaluated, further empirical investigation of its psychometric properties would be recommended to satisfy commonly accepted principles of survey development. The use of dichotomous measures of aspects of living situation arrangements permitted their incorporation into a correlational model. In some cases, this method resulted in collapsing some distinctly different circumstances together which may have masked the

actual effects of particular circumstances. This possibility may explain the failure to reveal the effect of an economic issue. Given adequate resources to develop and validate these variables, interval or ordinal scales that quantify these circumstances relative to each other could be used. Considerable effort would have to be invested in validating such an instrument.

Using level of injury as a measure of severity of disability is potentially inaccurate. Functional ability and level of injury are not necessarily equivalent. An alternative indicator could be the Barthel Index (Granger & Greer, 1976) which is a detailed assessment tool used in clinical settings to evaluate functional abilities such as mobility and self-care.

Implications

The findings of this study suggest many other avenues for future investigation. By identifying that the psychosocial factors locus of control, control over attendant services, and independence in how and where one lives, are significant components of self-esteem, questions arise regarding the influences which precipitate the development and expression of these factors. Certain aspects of the living situation, namely living in the community (as opposed to an institution) and in accommodation fully adapted for the person's desired level of functional independence, have been identified as significant correlates of these psychosocial factors. Therefore, it appears that these environmental factors may be somewhat influential in determining the psychosocial component. Longitudinal

research that gauges psychosocial factors such as locus of control, perceived control, and perceived independence over changes in living circumstances may reveal the mediating influence of aspects of the living situation.

Although the environmental factors regarding attendant care providers and the financial aspect of attendant care were not significant variables in self-esteem, these issues invite future investigation. As this study revealed, most people who are quadriplegic rely on a single person to provide their care. This fact raises questions regarding the effect of dependency on a single person for one's physical well-being and regarding the responsibility and stress placed on that care provider. Future research could investigate the implications of this circumstance for both the disabled person and the care provider, and the strategies by which people cope with this situation. Are there specific circumstances under which this situation causes more stress (for example, for a family member in comparison to a non-family member, or for a parent in comparison to a spouse)?

The financial issue investigated in this study included circumstances where the primary care provider is unpaid for his or her role and circumstances where the individual's access to funds to cover the cost of attendant care is dependent upon maintaining low income and assets. In all cases where the care provider was unpaid, that person was a family member (although not all family members were unpaid for their role). We do not know how or if this factor influences the well-being of the individuals involved or the relationship between them. For people who rely on conditional sources of funding for attendant care, research needs to

be conducted that investigates how this situation influences productivity and gainful employment.

Research on the most effective process for people who are quadriplegic to establish optimum living situations is needed. Do health care, rehabilitation, and independent living professionals need to direct people to these environments or is it preferable that disabled individuals direct themselves when they are ready? How much external assistance do people need to establish independence? What are the reasons that older people are more likely to live in institutional instead of community settings? Is their age the primary influence or are there other factors, such as finances or professional bias, that play a role?

These results also have implications for the practise of hospital and community-based rehabilitation. In keeping with the conclusions reached by Nosek, Parker, and Larsen (1987), it appears that severe physical disability and dependence for basic needs do not preclude effective independent living or positive self-esteem. The significance of living in an adapted environment indicates the importance of encouraging people, who are quadriplegic, to modify or seek accommodation that permits them to function as fully as possible.

Certain implications of these results are relevant to counselling people who are quadriplegic. First, the salience of locus of control and perceived control over attendant care (in predicting self-esteem) imply that people will benefit from enhancing their beliefs about and perceptions of their personal control. Counselling can attend to understanding the individual's sense of control and, if it

is weak, can proceed to assist him or her to develop a greater sense of power and competence over circumstances.

Second, a counsellor's empathy for the individual will be more easily attained by understanding the significant influence of certain characteristics of the living situation on aspects of personal control and independence. Living in a community setting (as opposed to an institution) and living in adequately adapted accommodation have appeared as correlates of perceived control and independence. Consequently, a counsellor will benefit from collecting information about living arrangements and the perceptions the individual has about his or her control and independence within these settings.

In relation to the former point, a third implication for counselling is to consider supporting individuals in changing their living circumstances if these factors appear to be limiting their progress in achieving a sense of control over their circumstances and their life. By initiating and following through on the process of altering their circumstances, it is likely that individuals will develop a stronger sense of their own power and ability to take control. However, the process of making changes can be difficult and long. Counsellors need to be sensitive to and understanding of the frustrations and challenges. They may also need to train the individual in problem-solving, assertiveness, and stress management skills so that he or she is adequately prepared to cope with the challenges and barriers. Furthermore, the counsellor may be able to link the individual with an advocate or agency who can advise on the resources available

to assist with achieving more desirable living circumstances.

In addition, these results have shown that family members are frequently assuming the role of primary care providers. Counsellors and other rehabilitation professionals need to be attentive to the effects of this chronic responsibility on issues such as stress and altered role expectations. Assistance in the areas of communication and coping skills and the development of strong support systems may help families to manage these circumstances effectively.

In summary, the results have provided limited support for the original hypotheses of the study. However, many interesting issues have been identified that warrant further empirical investigation and practical consideration.

REFERENCES

Ahmed, S.M., Valliant, P.M., & Swindle, D. (1985). Psychometric properties of Coopersmith Self-Esteem Inventory. Perceptual and Motor Skills, 61, 1235-1241.

Alvarez, S.E. (1985). Functional assessment and training. In H. Adkins (Ed.), Spinal cord injury (pp.131-154). New York: Churchill Livingstone Inc.

Anderson, T. & Andberg, M. (1979) Psychosocial factors associated with pressure sores. Archives of Physical Medicine and Rehabilitation, 60, 341-346.

Averill, J. (1973). Personal control over aversive stimuli and its relationship to stress. Psychological Bulletin, 80, 286-303.

Boschen, K.A. (1988). Housing options and preferences among urban-dwelling spinal cord injured young adults. Canadian Journal of Rehabilitation, 2, 31-40.

Bowers, K.S. (1968). Pain, anxiety, and perceived control. Journal of Consulting and Clinical Psychology, 32, 596-602.

Bracken, M.B., Shepard, M.J., Webb, S.B. Jr. (1981). Psychological response to acute spinal cord injury: An epidemiological study. Paraplegia, 19, 271-283.

Brown, M., Gordon, W.A., & Ragnarsson, K.T. (1987). Unhandicapping the disabled: What is possible? Archives of Physical Medicine and Rehabilitation, 68, 206-209.

Buchanan, L.E. (1987). An overview of spinal cord injury. In L. Buchanan & D. Nawoczenski (Eds.), Spinal cord injury: Concepts and management approaches (pp. 3-19). Baltimore: Waverly Press Inc.

Caywood, T. (1974). A quadriplegic young man looks at treatment. Journal of Rehabilitation, 40 (6), 22-25.

Coalition of Provincial Organizations of the Handicapped. (1986). Defining the parameters of independent living. Winnipeg, Man.: Coalition of Provincial Organizations of the Handicapped.

Consulting Psychologists Press. (1990). Personal communication.

Cook, D. (1979). Psychological adjustment to spinal cord injury: Incidence of denial, depression, and anxiety. Rehabilitation Psychology, 26, 97-104.

Coopersmith, S. (1967). The antecedents of self-esteem. San Francisco: W.H. Freeman.

Coopersmith, S. (1984). Self-esteem inventories. Palo Alto: Consulting Psychologists Press.

Cowan, R., Altman, H., & Pysh, F. (1978). A validity study of selected self-concept instruments. Measurement and Evaluation in Guidance, 10, 211-221.

Crandall, J.E. & Lehman, R.E. (1977). Relationship of stressful life events to social interest, locus of control, and psychological adjustment. Journal of Consulting and Clinical Psychology, 45, 1208.

Crewe, N. & Krause, J. (1987). Psychological aspects of spinal cord injury. In B. Caplan (Ed.) Rehabilitation psychology desk reference (pp.3-35). Rockville, M.D.: Aspen Publishers.

Crewe, N. & Zola, I. (1983). Independent living of physically disabled people. San Francisco: Jossey-Bass.

Crisp, R. (1984). Locus of control as a predictor of adjustment to spinal cord injury. Australian Disability Review, 1, 53-57.

Decker, S. & Schulz, R. (1985). Correlates of life satisfaction and depression in middle-aged and elderly spinal cord injured persons. American Journal of Occupational Therapy, 39, 740-745.

Decker, S.D., Schultz, R. & Wood, D. (1989). Determinants of well-being in primary caregivers of spinal cord injured persons. Rehabilitation Nursing, 14, 6-8.

DeJong, G. (1979). Independent living: From social movement to analytic paradigm. Archives of Physical Medicine and Rehabilitation, 60, 435-446.

DeJong, G., Branch, L.G., & Corcoran, P.J. (1984). Independent living outcomes in spinal cord injury: Multivariate analyses. Archives of Physical Medicine and Rehabilitation, 65, 66-73.

DeJong, G. & Hughes, J. (1982). Independent living: Methodology for measuring long-term outcomes. Archives of Physical Medicine and Rehabilitation, 63, 68-73.

DeJong, G. & Wenker, T. (1983). Attendant care. In N.M. Crewe & I.K. Zola (Eds.), Independent living for physically disabled people (pp.157-170). San Francisco: Jossey-Bass Inc.

DeLoach, C. & Greer, B. (1981). Adjustment to severe physical disability: A metamorphosis. New York: McGraw-Hill.

Denson, C.R. (1987). A descriptive study of independent living role models. Journal of Rehabilitation, 53, 59-64.

Dorr, D., Rummer, C.B., & Green, R.F. (1976). Correlations between Coopersmith's Self-Esteem Inventory and the California Test of Personality for children in grades four and six. Psychological Reports, 39, 221-222.

Erikson, E. (1963). Childhood and society. New York: Norton.

Ferington, F.E. (1986). Personal control and coping effectiveness in spinal cord injured persons. Research in Nursing and Health, 9, 257-265.

Fischer, E.G. (1989). Neurologic function after spinal cord injury. In A. Wang (Ed.) Spinal trauma (pp. 201-210). Philadelphia: Hanley & Belfus, Inc.

Frieden, L. & Cole, J.A. (1985). Independence: The ultimate goal of rehabilitation for spinal cord injured persons. American Journal of Occupational Therapy, 39, 734-739.

Frieden, L., Richards, L., Cole, J., & Bailey, D. (1979). I.L.R.U. sourcebook: A technical assistance manual on independent living. Houston, Tx.: The Institute for Rehabilitation and Research.

Glasser, W. (1984). Control theory. New York: Harper & Row.

Granger, C.V. & Greer, D.S. (1976). Functional status measurement and medical rehabilitation outcomes. Archives of Physical Medicine and Rehabilitation, 57, 103-109.

Green, B., Pratt, C., & Grigsby, T. (1984). Self-concept among persons with long-term spinal cord injury. Archives of Physical Medicine and Rehabilitation, 65, 751-754.

Hohmann, G. (1975). Psychological aspects of treatment and rehabilitation of the spinal injured person. Clinical Orthopedics, 112, 81-88.

Jenik, F. (1982). Social and vocational reintegration of paraplegic patients in Switzerland. Paraplegia, 20, 65-70.

Judd, F.K., Burrows, G.D. & Brown, D.J. (1986). Depression following acute spinal cord injury. Paraplegia, 24, 348-363.

Keith, R.A. (1984). Functional assessment measures in medical rehabilitation: Current status. Archives of Physical Medicine and Rehabilitation, 65, 74-78.

Kemp, B. & Vash, C. (1971). Productivity after injury in a sample of spinal cord injured persons: A pilot study. Journal of Chronic Disease, 24, 259-275.

Kerr, W. & Thompson, M. (1972). Acceptance of disability of sudden onset in paraplegia. International Journal of Paraplegia, 10, 94-102.

Krause, J. & Crewe, N.M. (1987). Prediction of long term survival among persons with spinal cord injury: An 11 year prospective study. Rehabilitation Psychology, 32, 205-213.

Lewis, P. & Blanchard, E. (1971). Perception of choice and locus of control. Psychological Reports, 28, 67-70.

Livneh, H. (1986). A unified approach to existing models of adaptation to disability. Part I: A model of adaptation. Journal of Applied Rehabilitation Counselling, 17, 5-16.

Lord, J. & Osborne-Way, L. (1987). Toward independence and community: A qualitative study of independent living centres in Canada. Ottawa: Department of the Secretary of State of Canada.

Malec, J. (1985). Personality factors associated with severe traumatic disability. Rehabilitation Psychology, 30, 165-172.

Mazzulla, J.R. (1984). The relationship between locus of control expectancy and acceptance of acquired traumatic spinal cord injury. American Archives of Rehabilitation Therapy, 32, 10-13.

McGowan, M.B. & Roth, S. (1987). Family functioning and functional independence in spinal cord injury adjustment. Paraplegia, 25, 357-365.

Murray, H. (1938). Exploration in personality. New York: Oxford University Press.

Nakajima, A. & Honda, S. (1988). Physical and social condition of rehabilitated spinal cord injury patients in Japan: A long-term review. Paraplegia, 26, 165-176.

Nickerson, E. (1971). Some correlates of adjustment by paraplegics. Perceptual and Motor Skills, 32, 11-23.

Nosek, M., Parker, R., & Larsen, S. (1987). Relationships among measures of psychological, social, and functional abilities for adults with severe muskuloskeletal impairments. Archives of Physical Medicine and Rehabilitation, 68, 840-845.

Nwuga, V. (1979). A follow-up study of paraplegics and tetraplegies discharged from a hospital. Journal of Tropical Medicine and Hygiene, 82, 30-33.

Pervin, L. (1963). The need to predict and control under conditions of threat. Journal of Personality, 31, 570-585.

Phares, E.J. (1968). Differential utilization of information as a function of internal-external control. Journal of Personality, 36, 649-662.

Phillips, L., Ozer, M.N., Axelson, P., & Chizeck, H. (1987). Spinal cord injury: A guide for patient and family. New York: Raven Press.

Ragone, D. (1987). Is it worth it?: A personal perspective. In L. Buchanan & D.A. Nawoczenski (Eds.) Spinal cord injury: Concepts and management approaches (pp.249-266). Baltimore: Waverly Press Inc.

Rogers, J. & Figone, J. (1979). Psychosocial parameters in treating the person with quadriplegia. American Journal of Occupational Therapy, 33, 432-439.

Rotter, J. (1966). Generalized expectancies for internal versus external control of reinforcement. Psychological Monographs, 80, (whole No. 609).

Shadish, W., Hickman, D., & Arrick, M. (1981). Psychological problems of spinal injured patients: Emotional distress as a function of time and locus of control. Journal of Consulting and Clinical Psychology, 49, 297.

Smith, N.K. & Meyer, A.B. (1981). Personal care attendants: Key to living independently. Rehabilitation Literature, 42, 258-265.

Statistics Canada. (1989). Health and activity limitation survey: Subprovincial data for Alberta. Ottawa: Canadian Government Publishing Center.

Stewart, T.D. (1977-78). Coping behavior and moratorium following spinal cord injury. Paraplegia, 15, 338-342.

Stover, S. & Fine, P.R. (Eds.). (1986). SCI: The facts and figures. Birmingham, AL.: University of Alabama.

Stover, S.L. & Fine, P.R. (1987). The epidemiology and economics of spinal cord injury. Paraplegia, 25, 225-228.

Swenson, E.D. (1976). The relationship between locus of control expectancy and successful rehabilitation of the spinal cord injured. Dissertation Abstracts International, 37, 1999A-2000A.

Thompson, D.D. & Dexter, W.R. (1980). Personality characteristics of spinal cord injury patients at injury and one-year follow-up. SCI Digest, 2 (Spring), 9-15.

Trieschmann, R. (1980). Spinal cord injuries: Psychological, social, and vocational adjustment. New York: Pergamon Press.

Trieschmann, R. (1988). Spinal cord injuries: Psychological, social, and vocational adjustment (2nd ed.). New York: Demos Publications.

Tucker, S. (1980). The psychology of spinal cord injury: Patient-staff interaction. Rehabilitation Literature, 41, 114-121.

Wiggins, S.F. (1983). Specialized housing. In N.M. Crewe & I.K. Zola (Eds.), Independent living for physically disabled people (pp.219-244). San Francisco: Jossey-Bass Inc.

Woodbury, B. & Redd, C. (1987). Psychosocial issues and approaches. In L. Buchanan & D. Nawoczenski (Eds.), Spinal cord injury: Concepts and management approaches (pp.187-217). Baltimore: Waverly Press Inc.

Woodrich, F. & Patterson, J.B. (1983). Variables related to acceptance of disability in persons with spinal cord injury. Journal of Rehabilitation, 49, 26-30.

Wright, B. (1983). Physical disability: A psychosocial approach (2nd ed.). New York: Harper and Row.

Vash, C. (1981). The psychology of disability. New York: Springer Publishing.

Young, J.S., Burns, P.E., Bowen, A.M., & McCutcheon, R. (1982). Spinal cord injury statistics: Experience of the regional spinal cord injury systems. Phoenix, AZ: Good Samaritan Medical Center.

Zejdlik, C. (1983). Management of spinal cord injury. Monterey, California: Wadsworth Health Sciences Division.

APPENDIX 1

INDIVIDUAL DATA SHEET

I.D. NUMBER _____

INDIVIDUAL DATA SHEET

DATE OF BIRTH: ___/___/___ AGE: _____
YR. MO. DAY

MARITAL STATUS:_____ SEX:_____

DATE OF INJURY:___/___/___ YEARS SINCE ONSET:_____
YR. MO. DAY

LEVEL OF INJURY:_____

EDUCATION LEVEL COMPLETED (BE SPECIFIC)

BEFORE INJURY:_____

SINCE INJURY: _____

EMPLOYMENT STATUS (BE SPECIFIC)

BEFORE INJURY: _____

SINCE INJURY: _____
(NOW)

LIVING SITUATION

Circle the statement that best describes your situation in the following categories.

(1) Location

(a) Own home, family home, group home (community)

(b) Institution, hospital, extended care centre

(2) Care provider(s)

(a) One primary care provider

(b) Staff of care providers

(3) Finances for attendant care

(a) My care provider(s) is not paid.

(b) I do not receive any financial support from any source (government, law settlement, or other) to pay my care provider(s).

(c) My care provider(s) is paid for their work but my personal income affects my access to finances to cover the cost of support services.

(d) My care provider(s) is paid for their work but my personal income has no effect on my access to finances to cover the cost of support services.

(4) Control

(a) I have some or complete control over the support services I receive (hiring, training, evaluation of staff).

(b) I have no control over my support services.

(5) Adapted living environment

(a) My home is wheelchair adapted so that I am able to do everything that I want to do and am physically capable of doing.

(b) My home is only partially or not at all adapted for my physical disability.

APPENDIX 2

COOPERSMITH SELF-ESTEEM INVENTORY

SAMPLE ITEMS FROM THE COOPERSMITH SELF-ESTEEM INVENTORY

ADULT FORM

Check either Like Me or Unlike Me

12. It's pretty tough to be me.

9. My family usually considers my feelings.

21. Most people are better liked than I am.

14. People usually follow my ideas.

Reproduced by special permission of the Publisher, Consulting Psychologists Press, Inc., Palo Alto, CA 94306, from Coopersmith Self-Esteem Inventory by Stanley Coopersmith. Further reproduction is prohibited without the Publisher's consent.

APPENDIX 3

ROTTER SCALE

SOURCE:

Rotter, J. (1966). Generalized expectancies for internal versus external control of reinforcement. Psychological Monographs, 80, (Whole No. 609).

Copywright 1966 by the American Psychological Association. Reprinted by permission.

I.D. NUMBER _____

ROTTER SCALE

INSTRUCTIONS:

This is a questionnaire to find out the way in which certain important events in our society affect different people. Each item consists of a pair of alternatives lettered **a** or **b**. Please circle the one statement of each pair (and only one) which you more strongly believe to be the case as far as you're concerned. Be sure to select the one you actually believe to be more true rather than the one you think you should choose or the one you would like to be true. This is a measure of personal belief: there are no right or wrong answers.

In some instances, you may discover that you believe both statements or neither one. In such cases, be sure to select the one you most strongly believe to be the case as far as you are concerned. Also try to respond to each item independently when making your choice; do not be influenced by your previous choices.

Please answer these items carefully but do not spend too much time on any one. Be sure to answer every one.

1. a. Children get into trouble because their parents punish them too much.
   b. The trouble with most children nowadays is that their parents are too easy with them.

2. a. Many of the unhappy things in people's lives are partly due to bad luck.
   b. People's misfortunes result from the mistakes they make.

3. a. One of the major reasons why we have wars is because people don't take enough interest in politics.
   b. There will always be wars, no matte how hard people try to prevent them.

4. a. In the long run, people get the respect they deserve in this world.
   b. Unfortunately, an individual's worth often passes unrecognized no matter how hard he tries.

5. a. The idea that teachers are unfair to students is nonsense.
   b. Most students don't realize the extent to which their grades are influenced by accidental happenings.

6. a. Without the right breaks, one cannot be an effective leader.
   b. Capable people who fail to become leaders have not taken advantage of their opportunities.

7. a. No matter how hard you try, some people just don't like you.
   b. People who can't get others to like them don't understand how to get along with others.

8. a. Heredity plays the major role in determining one's personality.
   b. It is one's experiences in life which determine what they're like.

9. a. I have often found that what is going to happen will happen.
   b. Trusting to fate has never turned out as well for me as making a decision to take a definite course of action.

10. a. In the case of the well prepared student, there is rarely if ever such a thing as an unfair test.
    b. Many times exam questions tend to be so unrelated to course work that studying is really useless.

11. a. Becoming a success is a matter of hard work, luck has little or nothing to do with it.
    b. Getting a good job depends mainly on being in the right place at the right time.

12.a. The average citizen can have an influence in government decisions.
b. This world is run by the few people in power, and there is not much the little guy can do about it.

13.a. When I make plans, I am almost certain that I can make them work.
b. It is not always wise to plan too far ahead because many things turn out to be a matter of good or bad fortune anyhow.

14.a. There are certain people who are just no good.
b. There is some good in everybody.

15.a. In my case, getting what I want has little or nothing to do with luck.
b. Many times we might just as well decide what to do by flipping a coin.

16.a. Who gets to be the boss often depends on who was lucky enough to be in the right place first.
b. Getting people to do the right thing depends upon ability, luck has little or nothing to do with it.

17.a. As far as world affairs are concerned, most of us are the victims of forces we can neither understand, nor control.
b. By taking an active part in political and social affairs, the people can control world events.

18.a. Most people don't realize the extent to which their lives are controlled by accidental happenings.
b. There really is no such thing as "luck".

19.a. One should always be willing to admit mistakes.
b. It is usually best to cover up one's mistakes.

20.a. It is hard to know whether or not a person really likes you.
b. How many friends you have depends upon how nice a person you are.

21.a. In the long run, the bad things that happen to us are balanced by the good ones.
b. Most misfortunes are the result of lack of ability, ignorance, laziness, or all three.

22.a. With enough effort we can wipe out political corruption.
b. It is difficult for people to have much control over the things politicians do in office.

23.a. Sometimes I can't understand how teachers arrive at the grades they give.
b. There is a direct connection between how hard I study and the grades I get.

24.a. A good leader expects people to decide for themselves what they should do.
b. A good leader makes it clear to everybody what their jobs are.

25.a. Many times I feel that I have little influence over the things that happen to me.
b. It is impossible for me to believe that chance or luck plays an important role in my life.

26.a. People are lonely because they don't try to be friendly.
b. There's not much use in trying too hard to please people; if they like you, they like you.

27.a. There is too much emphasis on athletics in high school.
b. Team sports are an excellent way to build character.

28.a. What happens to me is my own doing.
b. Sometimes I feel that I don't have enough control over the direction my life is taking.

29.a. Most of the time I can't understand why politicians behave the way they do.
b. In the long run, the people are responsible for bad government on a national as well as on a local level.

APPENDIX 4

ATTENDANT CARE QUESTIONNAIRE

I.D. NUMBER _____

ATTENDANT CARE QUESTIONNAIRE

This questionnaire is about your feelings about yourself in your current living situation. Please answer considering your current living situation. Indicate your honest reaction to the following statements, using these alternatives:

Strongly agree	**= SA**
Agree	**= A**
Disagree	**= D**
Strongly disagree	**= SD**

_____ 1. I control the attendant services that I use.

_____ 2. I expect attendants to follow my instructions in my personal care routines.

_____ 3. I have no influence on the quality of attendant care that I receive.

_____ 4. If I need assistance, I can receive it immediately or quickly.

_____ 5. My complaints about attendant services make no difference.

_____ 6. I can count on myself to manage problems with my attendant care.

_____ 7. I am in charge of my life.

_____ 8. In my current living situation, I can or do live on my own.

_____ 9. I worry about how quickly I can get emergency personal care assistance.

_____ 10. My schedule of personal care routines is not flexible.

_____ 11. I am free to decide how I spend my day.

_____ 12. I have choices in where I live.

_____ 13. In my current circumstances, my choices are limited because I do not have the funds for the services I need.

_____ 14. I am as independent as I can be.

APPENDIX 5

CONSENT FORM

CONSENT FORM

I, _____, hereby voluntarily
(print name)
consent to participate in the research study entitled "Living situation characteristics: Role in prediction of self-esteem of people who are quadriplegic".

I have been informed that the purpose of the research is to investigate differences in peoples' living situations and their thoughts and feelings about themselves.

I understand that I will complete four separate questionnaires and that it will take about one hour to do this.

I understand that I may choose to decline or discontinue my participation in this research project at any time.

I understand that my responses to the questionnaires used in this study will be kept confidential and will not be reported. I also understand that the questionnaires that I complete are coded with a number to ensure that my identity cannot and will not be revealed.

If I need further information now or at a later date, I can contact the researcher, Abigail Parrish-Craig, at either 438-5046 (work) or 433-3326 (home), or the project supervisor, Dr. Richard Sobsey, at 492-3755.

Signed: _____

Witness: _____

Date: _____